

**Public awareness, attitudes and beliefs about
intellectual disability: A Sikh perspective**

Gurpreet Kaur

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Overview

Part 1 is a literature review of South Asian perspectives on intellectual disability.

Thirty-one papers are reviewed according to seven geographical locations. South Asian needs, beliefs and knowledge about intellectual disability are highlighted. The limitations of the review are discussed as well as clinical implications and implications for future research.

Part 2 reports an empirical study looking at public awareness, attitudes and beliefs about the causes of intellectual disability amongst the UK Sikh community. The association between socio-demographic factors and these variables are examined and comparisons are made with a matched white British sample, through the use of a two-group comparison design. The results are discussed highlighting on the whole similarities between the groups.

Part 3 is a critical appraisal which focuses on the process of carrying out research with the UK Sikh community. Reflections on the literature review are discussed with reference to the scope of the review, the quality of the studies included and reasons for omitting potentially relevant articles. Key dilemmas and difficulties experienced whilst setting up the study are explored which focus on promoting the study and recruiting participants. Finally issues concerning data interpretation are discussed.

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Part 1: Literature Review

South Asian perspectives on intellectual disability:

An examination of knowledge, beliefs and needs

Abstract

Aim: To conceptualise South Asian perspectives of intellectual disability by drawing on global research.

Method: A literature review was carried out in order to identify all relevant articles. Thirty-one papers were gathered which were categorised according to the seven geographical locations within which they were carried out.

Results: Mixed views exist amongst South Asians regarding intellectual disability. Globally carers of individuals with intellectual disability suffer from a lack of support. Many South Asians hold theological and biomedical beliefs regarding intellectual disability simultaneously. Services are not utilised by South Asians due to a lack of knowledge about services available and a lack of culturally sensitive practices.

Conclusions: Services are required to adopt culturally sensitive and diverse approaches to supporting South Asian people with intellectual disability and their families. Suggestions for future research are made including the need to carry out empirical work on intellectual disability within a South Asian context focussing on specific religious groups.

Introduction

Intellectual disability in the West

Historically, Western descriptions of people with intellectual disability have ranged from ‘cretin’ and ‘moron’ to the more recently used labels ‘retarded’ and ‘mentally handicapped’. Some of these labels became outdated due to their pejorative nature and their associated levels of stigma (Sinason, 1992), although they are often still found in common parlance, usually as terms of insult. People with intellectual disabilities were only differentiated from people with mental health difficulties after the Mental Deficiency Act 1913 classified intellectual disability into four classes, namely idiot, imbecile, feeble-minded and moral defective.

Within the UK major changes materialised in the 1980s as people with intellectual disabilities were relocated from hospitals to small group homes to increase cost-effectiveness. This coincided with Wolfensberger’s (1972) elaborated concept of normalisation and the social model of disability which was gaining academic credibility. Recently, policies have emphasised key values of independence, choice and empowerment, promoted by ‘Valuing People’, (Department of Health, 2001, 2009). Internationally, the United Nations Convention on the Rights of People with Disabilities (2007) was adopted as a human rights instrument, in order to influence global perspectives regarding intellectual disability.

Intellectual disability in developing countries

In 2000, poverty in South Asia was higher than any other region of the world, except Sub-Saharan Africa (Thapa, 2004), with disability rates averaging around ten per cent (Voss, 2003), accounting for approximately 40% of the world’s poor. Within developing countries 80% of all disabled people live in poverty in isolated rural areas (Groce, 2008).

Gaps in the literature

Sell (1983) highlighted the importance of gathering information from families in South Asian countries in order to clarify the types of services required. However, South Asian service planners made structured attempts to offer support by planning according to existing services elsewhere (Nikapota, 1986), which were based on ‘well-intentioned Western exports of welfare ideologies’ (Miles, 1996). Today little is known about intellectual disability within a South Asian context beyond estimated prevalence rates, policy and carers perspectives. Therefore in order to fully understand the experience of South Asian people with intellectual disability and their families, it is essential to look beyond the Western framework.

Method

Scope of this review

The aim of this literature review was to identify papers which would help conceptualise intellectual disability from a South Asian perspective. A broad approach was adopted to capture as much relevant literature as possible, which was then refined using screening procedures. This review examines the existing literature via geographical location and discusses knowledge, beliefs and needs.

Search strategy

The following bibliographic databases were used for an initial search: PsycInfo, Medline, Embase, CINAHL and Science Direct databases. The initial search took place in July 2010 and aimed to capture as many relevant papers as possible. A broad date range was set, allowing for the incorporation of the earliest publications to those up to July 2010. Table 1 shows the keywords used for the search, chosen in order to reflect the three main areas of the review: intellectual disability, South Asian

and conceptualisation. Additional literature was identified by backward searching reference lists of key papers and hand searching key intellectual disability journals.

Table 1

Search string keywords

| Intellectual Disability | South Asian | Conceptualisation |
|--|---|---|
| intellectual disab*, learning disab*, disab*, retard*, handicap*, impair*, incapacit*, deform*, mentally handicap*, mentally retard* | South Asia*, India*, Bangladesh*, Sri Lanka*, Pakistan*, Nepal*, Maldives, Bhutan*, Ethnic* | conceptuali?ation, concept*, construct*, percept*, formulat*, attitud*, belief*, knowledge, understanding |

Note: * denotes truncation, ?denotes a wildcard term.

Inclusion and exclusion criteria

A large amount of papers were identified using the above search strategy. As a result consideration was paid to screening criteria, see Table 2.

Table 2

Inclusion and exclusion criteria for the literature review

| Criterion | Included | Excluded |
|-------------------|--|---|
| Conceptualisation | Attitudes, beliefs, formulations, knowledge, perceptions, understanding | Pathways to care, prevalence, service utilisation |
| Disability | Studies focussing on intellectual disability (in title and/or abstract), studies comparing intellectual disability and typical development | Studies on disability, comparative studies with other forms of disability |
| Language | English | Non-English |
| Population | South Asian including India, Bangladesh, Pakistan, Sri Lanka, Bhutan, Nepal and Maldives | Afghanistan, Burma and Iran and other non-South Asian studies |
| Article | Research/empirical | Discussion papers |

Results

The search produced over 100 articles, of which 31 were relevant. As the very nature of the review was to explore concepts which potentially differed from Western, scientific ideas surrounding intellectual disability, it seemed appropriate to include studies also likely to differ from the dominant rigorous scientific approach to research. Therefore, studies with less scientifically thorough methodologies and small sample sizes were included. The articles were divided according to countries where studies were carried out, of which seven were identified. The largest numbers of studies were carried out in India. Table 3 details the individual studies included in this review.

Table 3

Summary of studies on intellectual disability from a South Asian perspective by geographical location

| Authors & date | Location | Population | Sample size (N) | Design | Measures | Clinical implications |
|------------------------|---------------------------|---|-------------------------|------------|---|---|
| USA | | | | | | |
| Gabel (2004) | United states of America | North Indian Hindu immigrants | 20 (8 male & 12 female) | Interviews | Picture prompts, open ended questions & taxonomic trees | Implications discussed |
| UK | | | | | | |
| Azmi et al. (1997) | North West England | 13 Pakistani , 4 Gujarati, 3 Bengali & 1 Indian | 21 (12 male & 9 female) | Interviews | Interview schedule: 8 areas of importance, informed by previous research (Flynn, 1986, 1989; Prosser, 1989) | Recommendations for cultural observance and pro-activeness |
| Bywaters et al. (2003) | Birmingham & Coventry, UK | 14 Pakistani & 5 Bangladeshi families | 19 (11male & 8 female) | Interviews | Interview schedule informed by the National Survey of Parents caring for a Severely Disabled Child (Beresford, 1995). | Services need to work with families' beliefs |
| Croot et al. (2008) | North England, UK | 15 Pakistani parents & 1 Grandparent | 16 (12 male & 4 female) | Interviews | Informed by key informants from Pakistani community | Recommendations to assess beliefs by moving away from ethnocentric models |

| Authors & date | Location | Population | Sample size (N) | Design | Measures | Clinical implications |
|--------------------------------|-------------------|--|------------------------------|-------------|--|--|
| Emerson & Robertson (1998) | Birmingham, UK | 75 Pakistani, Bangladeshi & Indian parents & 20 South Asian intellectually disabled adults | 95 (34 male & 61 female) | Interviews | Structured & unstructured interviews | Increased culturally appropriate services |
| Fatimilehin & Nadirshaw (1994) | Leicester, UK | White, Muslim & Hindu families | 24 families, gender unstated | Interviews | Structured interview schedule | A need for increased service and worker cultural awareness |
| Hatton et al. (1997) | UK | Families of individuals with intellectual disability | 54, gender unstated | Interviews | Surveys & interviews | Recommendations for services to cater to needs of families |
| Hatton et al. (2003) | North England, UK | Pakistani, Indian & Bangladeshi families | 136, gender unstated | Interviews | A package of measures were used which were drawn from previous research (Baxter et al., 1990; Chamba et al., 1999; Hatton et al., 1998, 2002; Sloper & Turner, 1993) | Increased service awareness & disclosure support needed |
| Hepper (1999) | London, UK | Bangladeshi client | 1 female | Case report | No measures – case history | Cultural, social & ethical issues raised and need for more research |
| Sim et al. (2005) | Glasgow, UK | Carers (Pakistani & Hindu) and people with intellectual disability (Muslim, Hindu & Sikh) | 15 (7 male & 8 female) | Interviews | Semi-structured interview schedule | Description of strategies being employed in Scotland to address issues raised in study |

| Authors & date | Location | Population | Sample size (N) | Design | Measures | Clinical implications |
|---------------------------|----------------------|---|---------------------------|------------------------|---|---|
| India | | | | | | |
| Balasundaram (2007) | South Delhi, India | Buddhist, Hindu, Christian & Muslim mothers | 6 females | Interviews & one group | Interview schedule with 3 questions on religion | Discussion of results only |
| Edwardraj et al. (2010) | Vellore, South India | 29 mothers of children with intellectual disability, 17 CHWs & 16 teachers | 62 females | Focus groups | Discussion guide developed for study | Recommendations to practice cultural sensitivity/diversity |
| Gupta & Kaur (2010) | India | Parents (65 of children with intellectual disability and 30 of typically functioning children) | 95 (52 male & 43 female) | Interviews | A Quick Stress Assessment Test (QSAT) (Vaz, 1995) | Discussion of results only alongside cautioning of generalising the findings due small sampling |
| Lakhan & Sharma (2010) | Barwani, India | Parents - Tribal (N=28) & non-tribal (N=13) | 41 (24 male & 17 female) | Interviews | Questionnaires developed for study | Increased awareness of intellectual disability recommended |
| Madhavan et al. (1990) | Hyderabad, India | 393 (246 parents of typically functioning children, 67 teachers, 43 CHWs & 37 midwife trainees) | 393, gender unstated | Interviews | Case vignette and questions available for perusal | Recommendations for increased awareness and low cost training |
| Mathur & Nalwa (1987) | New Delhi, India | Parents (N=120) & typically functioning children (N=160) | 240 (120 couples) | Interviews | Structured questionnaire | Unstated |
| Murthy, Wig & Dhir (1980) | Ambala, India | Village leaders, CHWs & school teachers | 108, gender unstated | Interviews | Vignette & questions | The study led to the development of health education and training material |

| Authors & date | Location | Population | Sample size (N) | Design | Measures | Clinical implications |
|--------------------------------------|--------------------------------------|--|---------------------------|-----------------------------|---|--|
| Padencheri & Russell (2004) | South India | 23 couples | 46 (23 male & 23 female) | Structured interviews | The Intimate Bond Measure (Wilhelm & Parker, 1988) The Binet-Kamat Scale of Intelligence (Kamat, 1967) Gesell's Developmental Schedule (Gesell, 1940) Vineland Social Maturity Scale (Doll, 1935) | Further research on the influence of cultural and cognitive factors on the gender of the intellectually disabled child and the marital intimacy for parents. |
| Russell et al. (1999) | South India | Parents | 57, gender unstated | Randomised controlled trial | Parental Attitude Scale towards Management of Intellectual Disability (Bhatti et al., 1985). | Psycho-education material was developed for CHWs |
| Sharma, Singh & Thressiakutty (2006) | Hyderabad & Secunderabad South India | Mild and moderate intellectual disability, unemployed & in employment | 100 (76 male & 24 female) | Interviews | Developed 10 item rating scale measuring self advocacy and independent living skills 1) Vocational Placement Checklist (Thressiakutty, 1991) 2) Work traits questionnaire (Thressiakutty, 1991) 3) The General Aptitude Test Battery (Dolke & Sharma, 1975). | Training for self advocacy needed in special education curriculum |
| Suresh & Santhnam (2002) | Chennia, India | Men with mild intellectual disability (19) & moderate intellectual disability (26) | 45, gender unstated | Questionnaire | | Importance of assessing skills prior to vocational training highlighted |

| Authors & date | Location | Population | Sample size (N) | Design | Measures | Clinical implications |
|--------------------------------|----------------------|---|-----------------------------|--|---|---|
| Thressiakutty & Narayan (1990) | Secunderabad India | Parents | 100, gender unstated | Case analysis | Complaints and expectations analysis | Highlighted need for parents to be clearly informed about intellectual disability |
| Venkatesan (2004) | Karnataka, India | Parents of typically developing children (N=25), rehabilitation (N=53) & (N=72) medical staff | 150 (86 male & 64 female) | Questionnaire | A Knowledge and Opinion Questionnaire on Rights, Immunities and Privileges of Persons with Mental Retardation (KNOQ_RIP_MR) was developed | The KNOQ_RIP_MR was recommended for use to increase amongst professionals |
| Sri Lanka | | | | | | |
| Nikapota (1986) | Sri Lanka | Urban and rural families | 180 families | Questionnaire | Scheme of assessment for social competence | Highlighted need for early detection and parental education |
| Pakistan | | | | | | |
| Mirza et al. (2009) | Gujar Khan, Pakistan | Carers & primary health providers | 100 carers, gender unstated | Questionnaire, interviews & focus groups | Pathways to care, self-reporting & short explanatory model interview | Recommendations for increased awareness & training for healthcare professionals & community support |
| Nepal | | | | | | |
| Peters (1980) | Kathmandu, Nepal | Number and gender of participants | unstated | Anthropology | Unstated | Unstated |

| Authors & date | Location | Population | Sample size (N) | Design | Measures | Clinical implications |
|-------------------------|--------------------|---|--------------------------|---|--|---|
| Shrestha & Weber (2002) | Nepal | Individuals with intellectual disability | 9 (4 male & 5 female) | Case report | Case analysis | Further studies to identify the needs of older people with intellectual disabilities in Nepal and financial resources for such services |
| Bangladesh | | | | | | |
| Dhar (2009) | West Bengal, India | Families | 16 (9 male & 7 female) | Open ended Interviews | Theme of perceptions of living with a family member with intellectual disability | Recommendations for professionals to look at the familial impact of intellectual disability within therapy |
| Rao (2006) | Kolkata, India | Mothers & other family members | 8 females | Interviews & participant observations | | Recommendations for a broader approach to intellectual disability |
| Verma & Kishore (2009) | Secunderabad | Couples with intellectually disabled children | 60 parents | Interviews | Semi-structured interviews | Unstated |
| Zaman et al. (1987) | Bangladesh | Urban & rural general public, specialists & parents | 240 (80 from each group) | Interviews using semi – structured questionnaires | 1 for parents (22 items) and 1 for general public & specialists (17 items) | No clinical implications or recommendations were highlighted |

Note: - stands for ‘not applicable’,

‘Parents’ refers to parents with children with intellectual disability unless otherwise stated,

‘CHWs’ refers to community health workers.

South Asian perspectives of intellectual disability in the USA

Carrying out a two year ethnographic study, Gabel (2004) interviewed 20 first-wave¹ US Hindu immigrants. Having investigated South Asian Indian cultural beliefs for a number of years, Gabel clearly had access to the participants, although participant identification for the study was not clearly stated. Participants were highly educated, ranged in age from 25 to 85 and were all non-disabled. The aim was to explore linguistically how participants thought and spoke about intellectual disability.

Gabel (2004) reported that participants spoke about intellectual disability in accordance with religious beliefs. ‘Punarjanam’, viewed intellectual disability as the result of sins from a past life, and ‘karma’ emphasised the opportunity to learn lessons from a previous life by, for example, not complaining, and thereby accepting the disability. This in turn was seen as an opportunity to be released from rebirth (moksha). In this way ‘suffering through’ was viewed as an educational and beneficial experience, something to be embraced and not feared. Regarding labels, the most commonly used to describe intellectual disability was ‘mundh buddhi’ (slow brain). However, little agreement was found to exist as to the meaning. Some believed that it was a direct translation implying that a person had bad desires which were seen as unhealthy, sinful or dangerous. Others believed that a person’s slow brain affected their ability to learn. Some believed that the term referred to having a good mind but choosing not to use it due to laziness or lack of desire.

Overall, Gabel (2004) highlights definitions, causes and beliefs regarding intellectual disability. However, a key limitation was the lack of exploration of participants’ cultural beliefs within the larger American socio-cultural context.

¹ By first-wave, Chen (1999) refers to the phenomenon of immigrant populations over time, with the initial immigrants originally tending to arrive from wealthier backgrounds than those who came later.

South Asian perspectives of intellectual disability in the UK

Within the UK, Fatimilehin and Nadirshaw (1994) interviewed 12 white British and 12 South Asian families using a structured interview schedule. The aim of the study was to explore attitudes and beliefs about intellectual disability. Participants were identified through an adult day centre for people with intellectual disabilities in Leicester, UK. Time constraints were acknowledged as preventing random selection and a larger sample size in the study.

The study revealed that South Asians emphasised the role of religion and many families sought help by taking their child to a holy person. South Asian families were also more poorly informed than the white British families and were significantly less likely to know the name of their child's condition or its cause. Differences in service utilisation were also evident as the South Asian families did not use services, mainly due to religious and cultural reasons, as well as language barriers and a lack of available service information. Despite these findings, there was no straight forward dichotomy between the two samples. A key limitation of this study, acknowledged by the authors, was the exclusion of South Asian families classifying themselves as Buddhist, Sikh or Christian.

Hatton et al. (2003) studied a particular experience of services by South Asian parents. Participants from five education authority areas in the North of England were recruited from a variety of services for children with intellectual disabilities. Structured quantitative interviews with 136 South Asian parents were conducted in addition to semi-structured qualitative interviews with 26 South Asian parents over two time points. The aim of the study was to provide a rich picture of the disclosure experiences of South Asian parents with a child with severe intellectual disabilities.

It was reported that the disclosure process occurred relatively early in the child's life, with both parents being present in most cases and no differences were found between ethnic groups in relation to this. The majority of communication regarding disclosures took place in English and less than one third of the parents received written information. Just over half reported receiving adequate information, which was understood quite well in a language that was not too technical. However approximately twenty per cent of parents reported receiving a poor amount of information, which was hard to understand, quite technical and difficult to remember. Differences were also found between ethnic groups with Bangladeshi parents reporting a greater understanding of the diagnosis given compared to Indian and Pakistani parents. Indian parents were also less likely to have been told in their preferred language than Bangladeshi and Pakistani parents. Receiving information in a different language proved to be a barrier to parental acceptance as parents felt that medical understanding was very important in countering negative lay understandings of the intellectual disability. Hatton et al. (2003) stated that a good disclosure process could lead to long term benefits for families which could act as a crucial point of intervention for South Asian families.

Whilst Hatton et al. (2003) describe the benefits of good therapeutic input; Hepper (1999) reports dilemmas and cultural differences between professionals and clients. Describing a case report of a 27 year old Muslim woman with intellectual disability, Hepper aimed to explore the social and cultural context within which her arranged marriage took place and to understand the expectations placed on this individual following the marriage. This was deemed necessary in order to offer culturally appropriate social and psychological support and to moderate relapse stressors. Family members had differing beliefs; the mother believed the 'slowness'

would recede over time, the father assumed the ‘illness’ was treatable and that his daughter would eventually move away and live with her husband and extended family advised that marriage would help her ‘get over’ the ‘slowness’. Despite agreeing to marriage no discussion had taken place with the client about sexuality, pregnancy and motherhood. Three weeks following the marriage to a cousin in Bangladesh the husband became angry saying his wife was ‘inept’. Following this, she returned to the UK with her parents and deteriorated to the point that she was electively mute, neglected personal hygiene and refused food or medication. Severe weight loss and clinical dehydration resulted in a hospital admission.

Hepper (1999) highlights differing cultural perspectives. Professionals regarded the client as vulnerable and believed that the marriage had been traumatic, questioning her capacity to oppose parental decisions about marriage, unwanted sexual advances or unrealistic domestic demands. However, her family believed that marriage strengthened her social identity, reduced the stigma of the disability and allowed her to have a ‘normal’ adulthood. Normality was measured by the client’s ability to carry out domestic tasks and observe codes of modesty.

Whilst highlighting the need to negotiate between the advantages and disadvantages of different cultural perspectives, Hepper describes a professional dilemma regarding the resolution of ethical issues whilst keeping sight of the client’s vulnerability, for example, the right to education regarding sexuality. In summary, despite describing a single case history, Hepper (1999) highlights issues pertinent to cross cultural working and draws attention to the cultural, social and ethical issues that can arise.

Bywaters et al. (2003) explored the validity of negative stereotypical views held by some professionals about black and minority ethnic groups within the UK.

Families, fourteen Pakistani and five Bangladeshi, were selected from new referrals to the East Birmingham Family Service Unit, UK² between October 1999 and March 2000. The aims of the study were to explore families' understandings of the causes of their child's impairment, whether they felt shame and experienced stigma and the impact of these factors on service uptake and expectations of their child's future. These were related to four key stereotypes identified which have at times been blamed for poor service uptake, namely; (1) religious adherence, resulting in the belief that disability is a test or punishment; (2) greater sense of shame; (3) belief in God's will over human input and; (4) low expectations of the child's future and a reduced parental willingness to help the child achieve their maximum potential.

Discussion with parents highlighted that although some referred to God, more parents identified the cause as a consequence of either the mother's illness during pregnancy or the child's illness early in life. Four families stated consanguinity as a cause. Shame was experienced by parents who had been exposed to negative views about their child's disability. Little evidence was found that parents had failed to seek help, and no evidence was found linking low service uptake to religious beliefs and practices. Most of the families had extended families, but only three of those families had support. The authors concluded that a clearer understanding of disability, through appropriate information sharing, may empower parents to cope with the negative views of others. A limitation of the study was that no figures were stated in relation to the findings, leading to a difficulty with drawing conclusions.

Analysing perceptions of the causes of intellectual disability, Croot et al. (2008) recruited 16 Pakistani families through staff working in three schools in

² The EBFSU is a local project of a national voluntary sector organisation providing social care and social work services for children and families.

Northern England specifically for children with severe intellectual disability. The aim of the study was to explore how a small sample of Pakistani parents caring for a child with an intellectual disability understood and accounted for disability within their families and social groups.

The findings highlighted the existence of theological beliefs such as the child being a gift from God and bringing God's blessings through the responsibility of looking after them or through the promise of future salvation or reward. Some parents believed they were chosen by God or the child was seen as a test from God. Parents simultaneously held biomedical beliefs regarding the cause of disability. Some parents used a biomedical discourse to dispel what they viewed as judgemental and blaming attitudes within their extended families. Many parents in the study experienced high levels of stigma associated with their child's intellectual disability from their community and for this reason were reluctant to take their child to events within their community. Overall, parents often gave theological explanations but when faced with negative or unhelpful ideas, referred to biomedical explanations.

Drawing on a larger sample of 54 families, Hatton et al. (1997) explored experiences of South Asian carers of people with intellectual disabilities at least 14 years old. Participants were identified by professionals working within intellectual disabilities services across two boroughs in North West England. The aim of this study, relevant to this review, was to identify through the use of surveys and interviews, key issues faced by South Asian adults with intellectual disabilities and their carers. Almost all of the carers were mothers, Pakistani and were born outside of the UK. Findings highlighted that the majority of families experienced considerable material and social disadvantage and relatively small social support networks. The individuals with intellectual disability were also found to have

substantial care needs. The impact of the above factors on carers was reported to be considerable leading to high stress levels. A significant amount of hidden need was identified.

Reporting 21 users' needs, which seem to have been identified within the same study, Azmi et al. (1997) reported satisfaction levels. The least satisfaction was found to relate to racism and stigma experienced. Half of the sample wanted to move elsewhere with their family believing the bad treatment they experienced from their neighbourhoods was due to racism. The highest levels of satisfaction were with individual support received mainly from family members and interpersonal interaction with family members was also viewed positively.

The majority attended day services but reported a lack of cultural awareness and practice by staff. Satisfaction with leisure activities was mixed and half of the sample desired increased interaction with people from their own community. Socially and recreationally, activities included watching television, going out, shopping and visiting family and friends, but most participants were reliant on family to take them out. The majority felt that making friends was harder due to their intellectual disability and a similar amount felt their ethnicity made it harder. Nearly all described their primary identity in terms of their ethnicity and difference to white people, not their disability. Importantly, the findings clearly show that South Asian adolescents and adults are able to reveal a depth of information about their own experiences.

Also looking at individuals with intellectual disabilities, Sim and Bowes (2005) conducted semi-structured interviews with eight carers, who in total were looking after nine children with intellectual disabilities and separately with six people with intellectual disabilities, providing information on 15 people. The

research took place as part of a larger study on community care services for black and minority ethnic communities. Participants, who volunteered to take part, were gathered from services for people with intellectual disability. The aim of the study was to explore the extent to which the specific needs of South Asian people with intellectual disabilities were being addressed.

Sim and Bowes (2005) reported several issues which were common to a wide range of people with intellectual disabilities and their carers, namely issues of isolation, exclusion and feelings of stigmatisation. Issues pertinent to South Asians were described as the poor availability of service information. Those interviewed stressed the need for information to be communicated in minority languages and for the presence of Asian GPs or health visitors.

The final UK study to be reviewed was carried out by Emerson and Robertson (1998). The aim was to provide information on the future need for services for adults with intellectual disabilities from minority ethnic groups. This project had three stages. First, a census of all intellectually disabled children from minority ethnic group of statutory school age was undertaken. Second, relatives of 75 South Asian children and adults with intellectual disabilities were randomly selected from the census and interviewed and third, 20 interviews took place with South Asian adults with intellectual disabilities.

Relatives, usually mothers, of 40 South Asian children and 35 young adults with intellectual disability were interviewed in the first language of the carers' homes by a female interpreter. A structured interview was used, which was constructed for the Department of Health (Hatton et al., 2001) and consisted of a number of structured measures which were translated into Urdu, Hindi, Bengali and Gujarati. The results echoed the results from previous studies. Families were living in

considerable material disadvantage, had little support from extended family networks and felt little support from support groups or places of worship. Individuals with intellectual disabilities had high care demands which often placed restrictions on the lifestyle, physical and mental health of carers. Siblings were found to be the greatest source of help and carers stated that they would continue to care for their child rather than consider residential care. Carers were unaware of the range of support services that they could access, but viewed the few services they did access very positively. Separate single sex services were not wanted, but existing services were required to meet the cultural needs of users.

The interviews with users, all of whom attended some form of day service, focussed on different aspects of their lives. It was reported that users were positive about their home environment, the care they received and with the services they accessed. Some reported that they would like access to more day time activities, but most stated that evenings and weekends were the most limited in terms of activity, with few friends outside of the day centres. Most of the users were also aware of their ethnicity and religion and some of them wanted more recognition of culture and religion at their day service. Racism and stigma were rated the most negatively with more users reporting victimisation primarily due to their intellectual disability and a few reporting it also as a result of their ethnicity.

In summary, studies which have taken place in the UK have mainly focussed on the family experiences and views of intellectual disability, with a limited amount studying the views of people with intellectual disability. Several key findings seem to have emerged from the research. Fatimilehin and Nadirshaw (1994) reported that South Asians emphasised the role of religion more than white British participants and were more likely to see a holy person. They were also more poorly informed

about services, were less likely to understand their child's condition and to access services due to a lack of religious or cultural observance. Whilst Emerson and Robertson (1998) and Azmi (1997) reported high levels of satisfaction by service users, a need was also found to exist for increased activity and social outings. Some service users also wanted increased religious and cultural observance.

Reporting the needs of carers, Hatton et al. (1997), Emerson and Robertson (1998) and Sim and Bowes (2005) highlighted significant hidden need due to high levels of material disadvantage, increased levels of stress and low levels of support, knowledge and information about services available. Croot et al. (2002) reported the existence of mixed theological and biomedical beliefs held by parents of children with intellectual disability supported by Bywaters et al.'s (2003) research invalidating negative stereotypical beliefs about South Asian carers. Regarding service input, Hatton et al. (2003) emphasised the link between a good disclosure process and increased parental acceptance and finally Heppers (1999) raised cultural, social and ethical dilemmas when working in a culturally sensitive way.

South Asian perspectives of intellectual disability in India

The largest volume of studies in this review was carried out in India. As a result, studies will be described in the following five sections: studies on mothers; studies on parents; comparative studies; community studies and finally studies on people with intellectual disabilities.

The only study identified to focus exclusively on mothers was carried out by Balasundaram (2007) who highlighted the needs of six mothers with intellectually disabled children in Dakshinpuri, South India. The aim of the study was to highlight the experiences of these women and the theological issues they raised in a monthly self help group. It was found that none of the participants received emotional

support from their families, husbands or social support from the community; instead they experienced stigma and resented the way they were made to feel guilty. They feared others' judgements of them and some participants feared that their intellectually disabled child would cause 'revulsion' in others or put an extra burden on their immediate families. All of the participants who believed in God and practiced religious rituals increased their religious observance after learning of their child's intellectual disability in the hope that it would improve. However, participants felt that spending time in prayer was counter-productive, as it took up precious time and did not improve the child's condition. As a result religious observance lessened or stopped completely over time. All of the women valued the monthly self help group as it was the only support they received.

Six studies were identified which recruited parents in their samples, four of which focused exclusively on parents with children with intellectual disability and two were comparative studies with parents of typically developing children. The first parental study in Secunderabad, South India, involved the analysis of 100 parental interviews. Thressiakutty and Narayan (1990) carried out case note analysis with the aim of understanding and comparing parental complaints and expectations about their child with intellectual disability. Discrepancies were reported between complaints (N=319) and expectations (N=101). Although 19 parents complained about their child's tendency to wander and 18 about their inability to use money, none raised these issues when discussing expectations. Parents (N=13) described poor scholastic performance, yet only one parent expected educational support. Inappropriate social behaviour was a common complaint, but only four parents had expectations about managing behaviour. It is however unclear if these parents knew

about their support entitlements or understood that the behaviours of concern could be addressed with appropriate support.

A second study by Padencheri and Russell (2004) recruited parents from a facility for intellectually disabled children. Two groups of parents were formed from the 46 parents (23 couples) who took part; one group consisted of 16 couples who were parents of boys and seven couples who were parents of girls. A total of four standardised measures were administered with the aims of identifying whether the gender of the child with intellectual disability affected their parents marital intimacy and whether each partner's perceived intimacy between them differed.

A significant difference was identified. Intimacy between parents of girls with intellectual disability was found to be significantly impaired compared to parents of boys. Perceived intimacy within the dyads did not differ significantly between mothers and fathers. The authors highlighted that impaired marital intimacy should be regarded as a risk factor for psychiatric disorders and could predict aversive parent child exchanges. A need was highlighted to place greater importance in assessing marital intimacy among parents of girls with intellectual disability.

In order to assess the efficacy of interactive group psycho-education (IGP) on measures of parental attitudes towards intellectual disability, Russell et al. (1999) carried out a randomised controlled trial. Fifty-seven parents were recruited to the study from a facility for intellectually disabled children and were randomised to ten weeks of either a didactic teaching group or interactive group psycho-education (IGP), involving dissemination of information, discussion and problem solving tasks.

Pre-intervention, the groups were not well matched as higher scores were found in the didactic group in knowledge of and parental attitudes towards intellectual disability. Post intervention, there was a greater increase in parental

attitude and child rearing skills, followed by knowledge and attitudes towards management of intellectual disability among the IGP group, compared to the didactic group. Within the IGP group the improvement in attitude was better among parents of children with mild intellectual disability, than parents of children with moderate intellectual disability which was comparatively smaller in size. A key limitation of this study was that the study had strict inclusion and exclusion criteria limiting generalisation of the findings.

In a recent study on knowledge, Lakhan and Sharma (2010) examined the views of 41 parents of intellectually disabled children. All of the residents living in two blocks in the Barwani district were selected for this study. The aim of the study was to understand knowledge, attitudes and practices of families towards their children with intellectual disabilities. Participants were split into tribal and non-tribal groups, although definitions of these terms were not given.

Using questionnaires developed specifically for the study, it was found that groups, who were not in receipt of services, had misconceptions and lacked information about intellectual disability. Both groups showed a willingness to acquire new skills and knowledge in relation to managing their child's difficulties, but tribal parents were more empathic towards handling problem behaviour than non-tribal families who were described as 'demanding and pushy'. Daughters with intellectual disability were victimised and isolated more in the non-tribal community, whereas they were involved more in the tribal community.

In both groups, the majority of parents believed that intellectual disability was caused by sins from a previous life, which could be removed through prayer. They did not believe it resulted from poor nutrition or peri-natal problems. Faith healers were paid to use beating, burning and starvation methods in the name of

treatment and parent's advocated marriage believing it was a cure. In addition, bullying and teasing occurred in communities who believed that the intellectual disability was contagious. Despite a small sample, the results revealed a lack of awareness, leading to abusive forms of treatment in attempts to 'cure' the disability.

Comparing the views of parents with typically functioning and intellectually disabled children, Mathur and Nalwa (1987) interviewed 240 participants (120 couples) who were recruited from schools in New Delhi. The aim of the study was to investigate the prevalence of common misconceptions of intellectual disability. Using a structured questionnaire the authors found no difference in knowledge regarding causes. Fathers of children with intellectual disability were however highly misinformed. The capabilities of children were overestimated by just over half of parents with intellectually disabled children and just under half believed that their child could live totally unaided in a normal environment on attaining adulthood; although slightly less did not believe that their children would ever work. Over half of the same group believed that intellectual disability was curable; half believed so through prescribed medication, just over a quarter through marriage and one quarter through surgical intervention. Just under a quarter of parents believed intellectual disability was caused by 'karma' or an evil spirit. Parents of children attending special school were more accurate about intellectual disability and their child's future prospects than parents of children on a special school waiting list.

Researching the stress of parents with intellectually disabled children, Gupta and Kaur (2010) randomly selected 95 parents from three special schools and mainstream schools in Punjabi, India. Interviews using a structured measure were carried out with the aim of analysing the stress levels of parents and in particular examining the presence of mental and physical stress amongst parents of children

with intellectual disabilities. It was found that all parents displayed higher levels of mental than physical stress, and mothers were found to experience significantly higher levels of mental stress than fathers. Overall, parents of intellectually disabled children presented with more stress both mentally and physically than parents of typically developing children.

The next four studies focus on community views of intellectual disability. In their study, Murthy, Wig and Dhir, (1980) highlighted the importance of studying community attitudes prior to planning and organising services for people with intellectual disability in India. The study was conducted in what the authors describe as 'Raipur Rani Block' in the Ambala district of Haryana. The views of 108 village leaders, community health workers and school teachers regarding intellectual disability were gathered via the use of a vignette describing an intellectually disabled child, which was read to participants in their own language. Following this, a series of brief questions were asked with the aim of ascertaining ability to recognise intellectual disability and knowledge about causes, treatment and management.

Murthy, Wig and Dhir (1980) revealed that intellectual disability was viewed as a severe mental disorder by community health workers and rural village leaders and as a slight problem by school teachers. Whilst brain injury, malnutrition and weakness were mentioned, the majority of respondents considered fate to be the main cause of intellectual disability. However the preferred treatment approach was medical with a large number of the sample believing that improvement was possible with treatment. Without treatment, more than half the community health workers, school teachers and under half of rural leaders believed that the condition of a person with intellectual disability would worsen. A small number of community health workers emphasised the need for affection, attention and the right to education.

Staying with the family was reported as the preferred care option by the majority of the sample. Over half of the sample did not view marriage as an option and a high rate of rural leaders responded negatively to the marriage of a person with intellectual disability. Finally, although the majority of rural leaders and school teachers had seen a person with intellectual disability, just under half of the community health workers, arguably those most able to offer services and support, had rarely seen a person with intellectual disability and half had never seen one.

In a rural community study which took place in South India, Madhavan et al. (1990) studied the views of 246 parents, 67 teachers, 43 community health workers and 37 midwife trainees all from the general population. The sample was recruited from a primary health centre in the district of Andhra Pradesh which had 35 health centres distributed over 102 villages. Participants were presented with an unlabelled vignette and interviewed. The aims of the study were to assess recognition of intellectual disability and knowledge about causes, sources of help and actions that people would take if they came across a person with an intellectual disability.

Madhavan et al. (1990) found that a high number of participants recognised a problem, but a significant number were unsure as to what the difficulty itself was. Biological and environmental causes were rated highly by most of the groups, however, teachers felt that intellectual disability was caused by hereditary factors but also believed that it was the parents fault with many parents also blaming themselves. Medical management was rated highly and most respondents believed that a person with intellectual disability could be educated and work. In relation to what participants would do if they came across a person with an intellectual disability, more than half said that they would take the person to a Doctor, hospital or a mental hospital. Just over a quarter of teachers said that they would encourage

special education while around one tenth of each group stated that they would not know what to do. Ambivalence towards marriage existed. The majority of participants were unaware of services which existed.

Perceptions of intellectual disability were also studied by Edwardraj et al. (2010) in a rural part of India. Eight focus groups took place involving 62 women who were either mothers of children with intellectual disability, health workers and teachers in primary schools. The aim of the study was to explore issues related to how the community viewed intellectual disability.

Thematic framework analysis stressed teachers' beliefs in inadequate stimulation by parents as the cause of intellectual disability, resulting in a lack of tolerance towards parents. Mothers of children with intellectual disability attributed medical issues, peri-natal psychological trauma and consanguineous marriage as key causes of intellectual disability. Community health workers emphasised poor antenatal nutrition or delivery methods and did not envisage future improvement whereas teachers strongly believed in improvement with adequate stimulation. Fathers were highlighted as distant and unconcerned with the multiple demands on mothers, who were blamed by others, and blamed themselves, for the intellectual disability leading to guilt, depression, social ostracisation, abuse and marital separation. Some mothers also wished their child dead rather than face financial problems associated with their care. Community health workers felt that parents were unaware of resources and unwilling to seek help or follow instructions, as they lacked hope. Participants mostly agreed that individual faith improved ability to cope with difficulties rather than organised religious support.

Also assessing knowledge about intellectual disability in India, Venkatesan (2004) administered a questionnaire to 150 participants, 25 parents, 53 rehabilitation

staff and 72 medical staff, who were recruited from various professional services.

The aim of the study was to ascertain knowledge and opinions on rights, immunities and privileges for people with intellectual disabilities.

It was found that despite having a high number of professionals in the sample; respondents were only able to answer half of the questions on the measure correctly. It was also found that a number of negative attitudes existed, including the belief that parents of children with intellectual disability should pay higher school fees due to their extra needs. Tranquiliser use for controlling disruptive behaviour was endorsed as was the view that if hospitalised, people with intellectual disability should receive less attention, comfort or privileges than other patients. Finally, it was stated that people with intellectual disability in employment should be paid less due to a poorer rate and quality of work. Regrettably group comparisons were unavailable as group responses to items were omitted.

The final two studies to be described look at issues of employing people with intellectual disabilities. Sharma, Singh and Thressiakutty (2006) compared employed and unemployed people with intellectual disability, with the aim of analysing whether differences existed in achieving independent living and self advocacy skills. A total of 100 participants were recruited from various settings in the cities of Hyderabad and Secunderabad, South India. It was found that a higher level of self advocacy skills existed among the employed group and a higher level of independent living and self advocacy skills in people with mild intellectual disability than those with moderate intellectual disability. This can be further advocated from the findings of a study by Suresh and Santhanam (2002) who studied 45 individuals with intellectual disability, with the aim of understanding the relationship between generic skills, work traits and aptitude among people with varying types of intellectual

disability from different schools. The analysis of the adaptive skills, work skills and aptitude of people with mild and moderate intellectual disability from both special and mainstream schools found all three areas to be similar across groups which suggest that educational placements bare little relation to future vocational prospects. Overall it can be seen that increased access to mainstream resources leads to improved levels of functioning both in schools and in the workplace.

In summary, the studies which have taken place on intellectual disability in India have been reviewed according to five main areas. The views of mothers indicated low levels of support, high levels of stigma and a decrease in religious practice as a source of support (Balasandaram, 2007). Parental studies highlighted high levels of complaints and low expectations (Thressiakutty & Narayan, 1990); a decrease in marital intimacy for parents with a girl with intellectual disability (Padencheri & Russell, 2004); improvement in parental attitude and child rearing skills following interactive group psycho-education (Russell et al., 1999) and a lack of awareness alongside a willingness to learn about intellectual disability (Lakhan & Sharma, 2010). Comparative studies highlighted increased levels of stress experienced by mothers of children with intellectual disabilities (Gupta & Kaur, 2010) and a lack of knowledge about intellectual disability amongst parents of both typically developing and intellectually disabled children (Mathur & Nalwa, 1987). Community studies drew attention to high levels of stress and demands on mothers who had few resources to draw on (Edwardraj et al., 2010), little exposure to people with intellectual disabilities (Murthy, Wig & Dhir, 1980), poor knowledge of intellectual disability and negative attitudes about managing challenging behaviours amongst mainly professionals (Venkatesan, 2004) and poor knowledge about services (Madhavan et al., 1990). Finally, Sharma, Singh and Thressiakutty (2006)

and Suresh and Santhanam (2002) highlighted that increased access to mainstream services for people with intellectual disabilities leads to increased levels of functioning in schools and work.

South Asian perspectives of intellectual disability in Sri Lanka

The care needs of 180 intellectually disabled children were studied by Nikapota (1986) with the aim of identifying parental views. Urban families who received consultation at child psychiatric clinics were identified alongside rural families identified by community health workers. A standardised questionnaire was used to identify requests for help made by parents.

The results highlighted that following a preliminary meeting, just under half of the parents seen requested support in addition to a further quarter of parents during the meeting, mainly with support in teaching and training intellectually disabled children. The majority of highly educated parents accurately described their child's disability and requested help. In contrast just less than half of parents with no formal education had accurate knowledge of the disability and just over half requested specific help for their child. More parents with moderately intellectually disabled children requested special education than parents of severely intellectually disabled children, whose requests focussed on accessing residential care, due to insufficient support.

South Asian perspectives of intellectual disability in Pakistan

The views of 100 carers of individuals with intellectual disability from three rural and urban sites in Northern India were surveyed by Mirza et al. (2009). Participants were recruited from health centres within the Rawalpindi district. The aims of the study were to identify barriers to receiving care, beliefs about causation and management and to explore the experience of carers.

The results highlighted a delay between detection, and help seeking with many carers experiencing guilt for not noticing and seeking help sooner. Barriers to seeking help included a lack of information about intellectual disability amongst professionals and a lack of social support and health care available. There was also a lack of knowledge about the causation and effective interventions for intellectual disability across the sample. Explanatory models included social (pressure of modern life, Afghan war), the natural world (fever, drought) the supernatural world (Allah's choice, evil eye) and the internal world (fear, fatigue). Regarding expectations, a high number of carers expected an improvement in self care but only a quarter expected behavioural improvements. Some parents saw it as an act of faith to care for the child and sought guidance from traditional healers. Parents would also seek advice from teachers who were regarded as the most learned in the community.

South Asian perspectives of intellectual disability in Nepal

Using an anthropological approach to research, Peters (1980) stayed with the Tamang with the aim of understanding cultural beliefs about intellectual disability and compare them to Western beliefs. Through speaking to villagers and village leaders, Peters identified a classification system based primarily on 'linguistic incompetence' distinct from mental health difficulties. The system stated that intellectual disability was seen as the consequence of bad actions (karma). A female with intellectual disability was not considered to be of inferior status to other women, but a man with intellectual disability was deemed to be inept at fulfilling his duties and was prohibited from taking part in the customary inheritance of his father's land. As can be seen in Table 4, speech difficulties were treated as an important indicator of intellectual disability, however a lack of self sufficiency was also an indicator.

Table 4

Tamang intellectual disability classification system

| Tamang term | Severity | Translation | Behavioural indicators |
|--------------------|-----------------|--------------------|-------------------------------|
| Laato | Extreme | Dumb, stupid | Verbal incompetence, mute |
| Adha-laato | Mild | Half-dumb | Mild speech impediments |
| No label | Very mild | Not stated | Stuttering, lisping |

Unlike mental health difficulties, intellectual disability was not considered curable through traditional ritualistic means. Instead, the same love and care was given to children regardless of whether they were considered to have intellectual disability or not. It was also common practice for wealthy and religious families to foster intellectually disabled children in order to earn merit for a better rebirth. Marriage was not prohibited, but usually had to be arranged and although ridicule was not unheard of, it was considered to be in poor taste.

Peters (1980) stated that the criteria upon which the Tamang based their distinctions of intellectual disability were both similar and different to Western concepts. The Tamang, for example, may label a person with a speech problem due to poor hearing or some other physical impairment, as intellectually disabled, which would be less likely to occur in the West. Conversely, a person with mild intellectual disability from the West, with reasonable verbal ability, may easily assimilate into the Tamang society without such a label. Peters also noted a similar view in both cultures in relation to competency of speech. In the West, speech competence is an indication of intelligence and language difficulties amongst those with intellectual disability are common.

A second, more recent study carried out in Nepal aimed to explore the context and situation of adults with intellectual disability. A case analysis approach

was used on a convenience sample of individuals with intellectual disability drawn from five catchment areas, recruited using snowball sampling. Shrestha and Weber (2002) reported information about diagnosis, seeking services, family support and care giving, social integration and planning for the future. Regarding diagnosis, the majority approached a traditional healer to manage the problems they experienced. Although all of the parents reported their child's diagnosis as being given by a general physician, they did not receive positive assurance about the child's potential for future development. All reported poor educational services for their children. Most of the participants reported poor service utilisation when younger, but increased service use as they grew older. This was partly to do with an increased number of services and that all were from high middle class backgrounds, more likely to afford extra expenses with accessing services. Family support was seen as a prime resource, however most of the parents had made no future plans for their adult child with intellectual disability.

Overall, studies in Nepal have identified a classification system of intellectual disability based predominantly on language ability which has some overlap with Western classifications systems. Family support seems to be extremely important and children are cared for with the same amount of love given to typically developing children. Although the family appears to offer the primary source of care and support, there is also a lack of future planning by parents about their child's care. This is of particular concern due to the lack of services for older people with intellectual disabilities.

South Asian perspectives of intellectual disability in Bangladesh

The final section looks at four studies carried out in Bangladesh. The first study on Bangladeshi conceptualisations of intellectual disability (Zaman et al., 1987), aimed

to highlight thoughts, knowledge and beliefs about intellectual disability. A large sample of 240 randomly selected participants consisted of urban and rural general public, specialists and parents of children with intellectual disabilities (80 from each group). All participants were selected from the Dhaka area. One measure was administered to parents and another to the general public and specialists. Responses were categorised as grossly superstitious, unscientific, semi-scientific and scientific.

Scientific responses were given by the majority of the specialists, who mostly named pregnancy, delivery and post-natal care as potential causes of intellectual disability. The urban general public were more scientific than the rural public, a few of which gave grossly superstitious answers. Most of the rural general public and some of the rural parents believed intellectual disability was a curse from God. However, only a few of the rural general public and rural parents believed that it resulted from ancestors' sins. The participation of individuals with intellectual disabilities in religious and cultural events was supported by nearly all specialists and more than half of the general public believed that children had a right to education. Concerning treatment the majority of specialists thought that a psychiatrist held the responsibility; a large amount of parents suggested psychological treatment and paediatric input was suggested by the majority of the general public. All of the groups stated the main responsibility for care lay with parents.

A second study focussing on the definition of intellectual disability by eight Bengali mothers of children with intellectual disability was carried out by Rao (2006) through the use of focus groups. Mothers who were known to services as taking a proactive role in facilitating the inclusion of their children within their extended families and communities were specifically chosen for this study. The aim

of the study was not to generalise the findings, but to learn from families who enhance the inclusion of their children in 'natural' and 'unselfconscious' ways.

Rao (2006) described mothers as identifying their children as intellectually disabled due to two main criteria, 'normality' and 'mixing and mingling'. 'Normality' was deemed important as it demonstrated the ability to communicate thoughtfulness to others by fulfilling family roles and duties, and in turn taking on responsibility. The child's ability to 'mix and mingle', was also important as it involved knowing to whom and how to show respect, looking after guests and using respectful terms to address people. Intellectual disability was therefore defined using broader indicators than that of the medical model of intellectual disability. However discussions regarding children who did not behave 'normally' were neglected.

The third study looked at parental needs which were analysed with reference to their child's age, gender and intellectual disability severity by Verma and Kishore (2009). A total of 60 parents (30 couples), who attended therapeutic and rehabilitation services within which the authors worked, took part in the study.

A specific pattern of differences emerged as mothers' needs were related to emotionality, family and social care and fathers' needs to social aids and the child's future. Variability was also found in needs relating to the age of the child, with parents of older children having increased understanding of disability, service facilities and management techniques. Their queries also shifted towards issues concerning sexuality, marriage, vocation and future plans. However, parents of girls with intellectual disability were found to have more needs which may be related to research that Indian parents experience more stress in parenting a girl (Peshwaria et al., 1995; Shin et al., 2006). A key limitation is that the measure used was not discussed in depth.

Highlighting the experience of family members, the final study to be reviewed was carried out in West Bengal which encouraged carers to ‘tell their story’ about their child’s intellectual disability and the impact on their lives. Dhar (2009) interviewed 16 participants, who were identified using purposive and snowball sampling, with the aim of creating an in-depth understanding of the experiences of living with a family members suffering from intellectual disabilities.

A prominent experience was fear and constant tension related to unexpected events, for example, unpredictable violent outbursts. Parents also described feeling cursed or punished by God and unlike previous studies no positive theological aspects were expressed. Parents worried about future care for their child once they should die. Lack of empathy, support and understanding emerged as strong concerns. Societal responses manifested in terms of pity, sympathy and attempts to ignore or hide from the family with the intellectually disabled child. Maintaining control in front of others by limiting discussion about intellectual disability was deemed important. The disability label was attached to the entire family resulting in negative effects on siblings’ marriage prospects, increasing depression and demoralisation in the family.

Overall the studies in Bangladesh noted an emphasis on the family as primary carers (Zaman et al., 1987). Alternative definitions of intellectual disability were explored by Rao (2006) and the needs of mothers and fathers were found to differ and change with the increased age of the child (Verma & Kishore, 2009). Increased anxiety, worries about the child’s future, stigma were reported alongside decreased levels of support, a lack of positive theological beliefs and an attachment of the label disabled to the entire family were reported by Dhar (2009).

Discussion

This review highlights South Asian conceptualisations about intellectual disability as diverse and complex. It is clear that theological and biomedical beliefs exist side by side, and are strongly influenced by societal and cultural beliefs as well as context.

In some studies, participants were shown to switch between different belief systems in order to assist their coping ability, for example, shifting to a medical explanation to counter stigma and blame giving within their families and communities.

However, other participants appeared to hold fairly rigid beliefs and were less able to draw on resources in order to improve coping. This may have been because of adverse life circumstances, lack of exposure to biomedical information or because mixed beliefs may not have been explored by the studies presented.

Diverse needs have also been highlighted in relation to intellectual disability. Within South Asia, acceptance, support and respite have been absent for the majority of carers of individuals with intellectual disability. Instead, a blame culture seems to exist, emphasising mothers or past sins as the cause of intellectual disability.

Mothers have frequently been reported to be the main carers and it has been identified, have differing needs, which relate to emotionality, than to fathers who have at times noted to be absent from the demands of caring. Mothers instead are required to manage the numerous demands of caring for an intellectually disabled child whilst receiving little if any family or community support. The gender of the intellectual disabled child has also been noted to affect marital intimacy. For those living in rural areas, caring for an intellectually disabled child must be done whilst living in conditions of material deprivation. The needs of individuals with intellectual disability interested in education and working could be met by increased access to mainstream resources.

In the UK, the needs of individuals with intellectual disability have been emphasised slightly more. Day services are requested to observe cultural and religious practices, increased social activity would benefit both carers and those cared for as would more accessible information about services. Professionally, there is a need to dispel stereotypes about South Asian carers and further research needs to be conducted in relation to cultural, social and ethical issues when working with South Asians in intellectual disability services. Both in South Asia and in the West it can be seen that it is essential to work sensitively, encompassing cultural diversity and alternative working practices in order to meet the needs of South Asians with intellectual disability and their families. This is all to be balanced alongside a need for professionals to maintain ethical practice when working with conflicting cultural values.

The UK has attempted to not only offer services to South Asian people with intellectual disability, but has also made efforts to review service inefficiencies and called for improvements to tackle the double discrimination faced by this group. Stereotypical views held by professionals have been challenged and emphasis on the disclosure process has highlighted it as an essential point of intervention for engagement and for offering future support.

In contrast, access to services in South Asia have appears to be limited, either due to carers' numerous demands taking away the time needed to access services, or due to a lack of services. The most research into the experience of those living with individuals with intellectual disabilities has been carried out by researchers in India, compared to other researchers in other South Asian countries. However, of great concern, is that despite the services being offered, knowledge about services is scarce.

Limitations of the review

This review attempted to conceptualise intellectual disability in the context of a broad range of South Asian ethnic and religious communities. Whilst attempts have been made to separate the literature into coherent sections, it is clear that the enormity of the task has inevitably led to an overlap regarding certain issues. Although firmer conclusions regarding the evidence on public beliefs, attitudes and knowledge would undoubtedly be greatly welcome, the diverse methodologies employed in the studies reviewed, the range of issues raised and the numerous methodological limitations noted would seem to make firm conclusions inadvisable. Finally it should be noted that due to its focus on the empirical literature, this review excluded discussion papers, which perhaps could have led to a more comprehensive understanding of conceptualisations of intellectual disability in South Asia and the UK, particularly regarding initiatives.

Clinical Implications

This review highlighted a number of important areas which clinicians should take note of when working with South Asians with intellectual disabilities or their carers. Primarily, no clear cut dichotomy was found to exist between ethnic groups in relation to beliefs, attitudes or knowledge about intellectual disability. However, a number of groups were categorised under the term 'South Asian' in this review, due to a low number of studies, focussing on any particular South Asian group. Therefore caution is urged in drawing firm conclusions when comparing different communities. The current findings suggest that different facets of religion beyond explicit religious faith may be important for clinicians to enquire about. Accessing holy persons in order to seek cures for the intellectual disability have been noted to commonly take place both in South Asia and in the West. Holy people may therefore have a strong

influence on the attitudes and beliefs of carers for people with intellectual disabilities. Community leaders have in the same way been found to influence community attitudes towards intellectual disability as well as influence important factors such as the marriage of a person with intellectual disability. Also, personal religious practice has been found to have differing effects on carers, for example, either drawing them towards religion for support or further away as it provides no immediate answers. Clinicians should explore these issues with carers of people with intellectual disability in order to fully understand religious factors which may influence their beliefs and attitudes.

Some of the studies suggested that more effort needs to be made by services to cater to the religious and cultural needs of their users. Clinicians should help to facilitate this process as is likely to lead to increased levels of satisfaction. Within South Asia carers would benefit from sensitive and creative exploration from professionals regarding respite and support, within a complex network of responsibility and stigma. More funding is clearly required to increase the number of accessible services for carers of individuals with intellectual disability.

Implications for future research

The research presented within this review has focussed mainly on families living with individuals with intellectual disabilities in the US, UK and South Asia. Only a handful of studies which had taken place in South Asia described detailed methodologies. No study seems to have taken place incorporating a large sample size across several areas in South Asia. Studies to date have mostly focussed on homogenous South Asian groups, with little research on specific South Asian populations. Although studies have highlighted the importance of religion for South Asians in terms of their understanding of intellectual disability and their coping

strategies, to date no empirical work on intellectual disability within a South Asian context has focussed on any specific religious group. Research into Hinduism, Islam, Christianity, Buddhism, Jainism or Sikhism may offer a fresh insight into existing knowledge, beliefs and attitudes held by members of South Asian religious communities.

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Part 2: Empirical Paper

Public awareness, attitudes and beliefs about
intellectual disability: A Sikh perspective.

Abstract

Aims: To explore UK Sikh lay people's awareness, attitudes and beliefs about intellectual disability and to assess the influence of socio-demographic factors on responses. The findings were also compared to a matched white British sample.

Method: Sikh participants were recruited via snowballing and incentivised recruitment. The study was also promoted on popular Sikh internet forums, blogs and websites, a Sikh radio and a Sikh TV channel. In total 253 UK Sikh adults took part in the survey; subsequently a matched sample of 259 white British adults was provided by the project supervisor. Participants were required to complete a brief, completely anonymous survey either online or in paper format. The survey comprised of a part of the Intellectual Disability Literacy Scale for assessment of knowledge, beliefs and attitudes (IDLS) and the Community Living Attitudes Scale-Mental Retardation version (CLAS-MR). Minor adaptations were made to tailor the measure to the target audience, prior to being translated into Punjabi.

Results: Statistical analysis highlighted that overall there were very few significant differences between the Sikh and white British samples. Equal proportions of each sample were able to recognise intellectual disability on the basis of an unlabelled vignette; Sikhs were slightly more likely to attribute causes to religion or fate and slightly less likely to endorse inclusion than white British participants. Desire for social distance decreased with increased levels of religious importance for both groups.

Conclusions: This study highlights interesting issues regarding the similarity of responses by both groups. Recommendations for further research are discussed in order to fully understand the relationship between religion and intellectual disability.

Public awareness, attitudes and beliefs about intellectual disability:

A Sikh perspective

Introduction

Founded in 1469AD by Guru Nanak Dev in Punjab, Sikhism is one of the world's youngest religions with worldwide population estimates approximating 25 million. Unlike Hinduism, Sikhism does not promote idol worship and rejects caste and gender differences; instead Sikhism propagates equality and is monotheistic, believing in the existence of one God for all rather than offering diverse belief systems. Like Islam, Sikhism places extreme importance on praying and giving in charity but does not advocate fasting, circumcision or pilgrimages. Sikhism emphasises truthful living, contentment, humility and compassion, attainable through meditative practice and selfless charitable service. Those who choose to be initiated into the Sikh way of life are known as 'Khalsa', meaning 'pure ones'.

According to the 2001 UK Census, 336,000 individuals identified themselves as Sikh, totalling 11% of the non-Christian religious population and in turn the fourth largest UK religious group after Christianity, Islam and Hinduism. However, key UK Sikh leaders felt that the 2001 census lacked the necessary Sikh category options which in turn resulted in an inaccurate categorisation of responses. Current estimates exceed 600,000 (UK Sikh Federation, 2011), potentially making Sikhism the third largest UK religious group. However, despite their large numbers Sikhs are rarely the unique focus of research and if studied at all, are usually amalgamated into the umbrella group 'South Asian', which neglects their unique identity.

Sikhism, mental health and disability

The Sikh religion attributes the cause of mental suffering to an individual's perception that the ego (ahankar) is an authentic centre (Sandhu, 2005). The ego's

desire to be different from others results in a struggle for existence and permanence (Kaur, 1985) leading to stress and despair in life (Maskeen, 1993). Alongside the ego stand four further vices known as lust (kam), anger (krodh), greed (lobh) and attachment (moh) all of which are believed to prevent the consciousness from realising its true purpose of accessing the spiritual self (Sandhu, 2005).

While several studies in the mental health field have included Sikhs in their samples (Hashemi & Cochrane, 1999; Orford et al., 2005; Robinson, 2009; Schmitt et al., 2010; Sembhi & Dein, 1998), no studies to date have been published which exclusively explore the Sikh understanding of mental illness. Similarly, only a few studies on South Asians and disability have included Sikhs within their samples, but are limited to understanding carers' experiences (Katbamna et al., 2004) and women's perspectives on disability (Hussain, 2005). Studies regarding intellectual disability have made no specific reference to Sikhs, whilst providing some understanding of intellectual disability in the context of Islam and Hinduism (Fatimilehin & Nadirshaw, 1994; Hatton et al., 2003). While this may be explicable in terms of the larger number of Muslims and Hindus both globally and in the UK, where a lot of research on South Asians has been conducted, the wholesale omission of Sikhism from the literature seems curious. Miles, (1995) for example, in discussing religion and disability within an Eastern religious context considered disability within Judaism, Christianity, Islam, Hinduism and Buddhism, but had nothing to say on the Sikh doctrine. One possible explanation of this omission may be that the main Sikh scripture, the Guru Granth Sahib Ji makes no specific reference to intellectual disability in relation to physical, mental or social impairment (Raji, 2009). Instead, any mention of disability refers to an inability to progress spiritually.

In talking about their spirituality, the first Sikh Guru, Guru Nanak Dev (1708), was recorded as saying ‘I am blind, mute, crippled and totally lacking in understanding’.

Intellectual disability within the Sikh population

The prevalence of intellectual disability within the UK or worldwide Sikh population is unknown, which inevitably creates a need to extrapolate data from research about South Asians generally. The suggestions from this data are however not clear cut as estimates of intellectual disability prevalence among South Asians within the UK differ. Emerson et al. (1997) estimated intellectual disability to be three times more common among South Asians compared to the white British population, in line with Kerr (2001). However this was disputed by McGrother et al. (2002) who suggested a similar prevalence among South Asians and the white British population. Such differences may result from the difficulty in estimating prevalence of intellectual disability amongst ethnic groups in the absence of epidemiological research (Raghavan & Small, 2004; Emerson & Hatton, 2004). While accurate figures are lacking, it is clear that, at the very minimum, there is a need for intellectual disability services to cater towards the needs of South Asians within the UK, as comprehensively as they do for the white British population.

Of primary importance is the issue of service uptake. It has been found that South Asians with intellectual disability have increased support needs, yet low service uptake, due to a lack of knowledge of services available, language barriers and service insensitivity to their needs and values (Atkin & Ahmed, 2000; Chamba et al., 1999; Fatimilehin & Nadirshaw, 1994; Hatton et al., 1997, 2003 & Mir et al., 2001). Negative stereotypical assumptions have also been found to exist among health professionals leading to institutional discrimination (Bywaters et al., 2003).

It has also been suggested that Western approaches to intellectual disability are out of sync with traditional South Asian values and practices (Thomas & Thomas, 2002a, 2002b; Miles, 2010). This in turn raises the question how South Asians who immigrated to or were born in Western countries experience intellectual disability services. Gabel (2004) found that South Indian immigrants living in the US had beliefs about intellectual disability which differed substantially from the beliefs rooted in the country's educational system, regardless of their length of residency. Hindu religious philosophies heavily influenced beliefs amongst this group who predominantly understood intellectual disability in terms of 'karma'. As a result, the presence of a person with intellectual disability within the family was seen as an opportunity to understand lessons from a past life to improve current actions.

It may be that acculturation alone may not shift belief systems and that the attitudes and behaviours of South Asians living in Western countries in relation to intellectual disability may differ substantially from the host culture. An inherent disparity between belief systems may result in poor service uptake and poor retention of South Asians with intellectual disability and their families leading to an absence of assessment, intervention, education, care and support.

Of particular concern, early detection of intellectual disabilities is delayed amongst the South Asian population (Mirza et al., 2009; Bywaters et al., 2003; Fatimilehin & Nadirshaw, 1994). Carers, mostly mothers, have been found to feel guilty about delayed diagnosis often blaming themselves for causing the intellectual disability (Edwardraj et al., 2010). Support from family or friends has consistently been found to be scarce (Hatton et al., 1997; Balasundaram, 2007; Dhar, 2009; Mirza et al., 2009) and it has been noted that South Asian communities hold negative

stereotypical assumptions about the causes of intellectual disability, often attributing it to past sins (Gabel, 2004, Lakhan & Sharma, 2010; Zaman et al., 1987). Within the UK, Hatton et al. (1997) highlighted increased stress levels among South Asian carers, putting a majority of them at risk for developing mental health problems.

Due to a fear of the stigma associated with having a child with an intellectual disability, South Asian families have been found to avoid attendance at places of worship in order to minimise interactions with members of their community (Croot et al., 2008; Islam, 2008). The impact of stigma is experienced not only by parents, but also by siblings, potentially affecting future marriage prospects (Dhar, 2009). Females with intellectual disability have been noted generally to hold the lowest status within South Asian communities and, in India, it has been found that parents from the Punjabi, particularly from the Sikh religion, access medical services less for their young daughters compared to young sons (Booth & Verma, 1992).

South Asian parents have been found to have unrealistic expectations about the prognosis of their child with intellectual disability (Black, 1997). Of note, they tend to have numerous complaints regarding their child's behaviour, yet have fewer expectations about behavioural improvements and future prospects (Thressiakutty & Narayan, 1990). Misconceptions about marriage and medication as potential cures for intellectual disability have also been reported (Peters, 1980; Marthur & Nalwa, 1987). Theological beliefs on the whole have been studied according to ethnic identity, with few studies focussing on religious groups. Whilst studies have highlighted a belief in fate or God as the cause of intellectual disability, results also highlight attribution to biomedical causes (Croot et al., 2008). A complex mix of beliefs seems to exist, which highlights the importance of professionals making efforts to incorporate diverse beliefs systems into their work with South Asians with

intellectual disability and their families (Azmi et al., 1997; Croot et al., 2008; Edwardraj et al., 2010; Fatimilehin & Nadirshaw, 1994; Madhavan et al., 1990; Pal et al., 2000).

While the research carried out to date makes a useful contribution to our understanding of intellectual disability within a multicultural society, a number of important limitations should be noted. The evidence reviewed is mostly based on small samples and poor methodological procedures, for example, in most of the studies, no control groups were used. If used, the control groups appeared to be poorly matched. There was also very little random sampling used in the studies leading to unrepresentative findings. The views of parents of individuals with intellectual disability have been the usual focus of enquiry, with very few studies focussing on general population perceptions of intellectual disability. As noted, studies have either looked at South Asians generally or specific ethnic groups, but have largely neglected religion as a factor. Whilst some authors have considered intellectual disability in the context of Islam (Miles, 1995) and Hinduism (Gabel, 2004; Miles, 1995), intellectual disability in the context of Sikhism has not been investigated. The current study aimed to address these gaps in the literature by examining awareness, attitudes and beliefs regarding intellectual disability among Sikh lay people in the UK. In particular, the following questions were addressed:

- 1) Are members of the Sikh community able to recognise symptoms of intellectual disability in response to an unlabelled vignette?
- 2) What beliefs about the causes of intellectual disability are found in the UK Sikh community?

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- 3) What attitudes to the inclusion of people with intellectual disability are prevalent?
 - 4) What levels of social distance do the UK Sikh community desire towards people with intellectual disability?

For all questions, Sikhs will be compared to a matched white British sample and socio-demographic variables, such as ethnicity, age, gender, education, religion, importance of religion, frequency of attendance at a place of worship and prior contact with intellectual disability, will be examined.

Method

Overview and design

This study was undertaken alongside a much larger, separate, population survey comparing knowledge, attitudes and beliefs about intellectual disability within different ethnic groups. A number of South Asian groups were included in Scior and Furnham's (2011) study, but very few responses were obtained from Sikhs. As a result the current study adopted a two independent samples design comparing the views of Sikh adults residing within the UK to a white British sample.

Power analysis

Calculation of the required sample size was informed by Scior and Furnham (2011). In their study comparing beliefs about intellectual disability and schizophrenia of white British participants, UK South Asians, UK black Africans and East Asians, a small average effect size of 0.2 was found. Being the most relevant research to the current project, this effect size was used for a power calculation. Assuming equal group sizes, the power calculation was carried out using the G*Power 3 computer programme (Faul, Erdfelder, Lang & Buchner, 2007), specifying alpha = 5% and desired power = 80%, using ANOVA as a proposed test. The analysis indicated a required sample size of 416; 208 participants per group.

Participants

A convenience sample of 253 UK Sikh adults aged 16 and over were recruited for this study, 245 Sikhs were of South Asian origin and eight were from other ethnic backgrounds. A comparison sample of 259 white UK residents was drawn from data gathered in a separate study by Scior and Furnham, (2011). Both data sets were collected concurrently. Participants were recruited on the basis of both religious and ethnic identity. Participants to the first sample (N=253) were recruited on the basis of identifying themselves as belonging to the Sikh religion and ethnically of South Asian origin, with the exception of eight participants who were Sikh but from other ethnic backgrounds. The comparison sample (N=259) were white British residents who defined their religion as either Christian or under the broad category of 'atheist, agnostic or non-religious'. Throughout the thesis the two groups will be called 'Sikhs' and 'white British participants', even though it is acknowledged that this categorisation conflates religion and ethnicity.

Initially, snowball sampling for the Sikh sample took place by promoting the study to the researcher's network of Sikh contacts. Following a dearth of responses, internet recruitment took place, which involved advertising the study on popular Sikh forums, blogs and websites. The research was also promoted on a popular Sikh Sky TV channel and one Sikh radio station. Numerous attempts were made to advertise the research in Sikh newspapers and other Sikh media channels but these unfortunately proved to be unsuccessful. Finally, letters and posters about the study were sent to popular Sikh temples (Gurdwaras) across the UK, particularly during important events in the Sikh calendar, in order to target large numbers of Sikhs. Contact with Gurdwaras was made via post and e-mail when available, requesting

that the posters advertising the survey be displayed, in both English (see Appendix 1) and Punjabi (see Appendix 2).

When a member of the Gurdwara committee was known to the researcher, face to face conversations took place about the study. Advertisements specified the study's uniform resource locator (URL) in addition to the researcher's contact details via tear-off slips, thereby enabling participants to complete the survey online or to contact the investigator directly for a hard copy of the survey.

As an incentive, all participants were invited to submit their contact details if they wished to be entered into a prize draw for retail vouchers in the value of £50. In order to enhance the number of participants, incentivised recruitment (Gardner, 2009) was also used by offering participants the chance to win a £25 cash prize for promoting the research and gaining participants. An item was inserted at the end of the questionnaire asking participants to give the name and contact details of the person who had alerted them to the research, if they so wished.

Measures

With social inclusion being a key target for international policies, it was deemed important that public attitudes, beliefs and knowledge about intellectual disability were captured through the use of an efficient measure. However, a number of measures were found to focus predominantly on attitudes towards intellectual disability, neglecting other responses such as awareness and beliefs (Antonak & Harth, 1994; Henry et al., 1996a).

Measuring knowledge, beliefs and attitudes

The Intellectual Disability Literacy Scale (IDLS; Scior & Furnham, 2011) was deemed to be the most appropriate measure for this research. The IDLS is a comprehensive, recently developed measure which assesses the relationship between

four aspects of intellectual disability literacy. The IDLS has been found to have good psychometric properties for presentation of symptoms of mild intellectual disability. The psychometric properties of the IDLS were presented by Scior and Furnham, (2011), who concluded that the measure has an easily interpretable factor structure and good internal consistency across all of the subscales. Test-retest reliability for all aspects of the measure has also been reported as acceptable. The measure ascertains information about the ability to recognise symptoms of intellectual disability and to distinguish them from other mental health problems. It also draws attention to the area of beliefs about the causes and suitable intervention of intellectual disability. The fourth aspect of the scale looks at desire for social distance from individuals with intellectual disabilities as a measure of external stigma (Link & Phelan, 2001). The IDLS has been shown to have good reliability for the purposes of cross-cultural research. For the purposes of this research, the IDLS sections on recognition, causes and social distance were used. Information on emotions and treatment beliefs were also gathered as the data from the research was also intended to contribute to the larger project and a large multi-cultural validation study run by the project supervisor. The results from the other sections are to be analysed at a later stage.

Measuring attitudes towards people with intellectual disabilities

The Community Attitudes Living Scale-Mental Retardation Form (CLAS-MR) designed by Henry et al. (1996) was chosen for this study. The CLAS-MR has been validated across a number of cultural contexts (Henry et al., 1996a; 1996b; Horner-Johnson et al., 2002; Schwartz & Armony-Sivan, 2001; Yazbeck et al., 2004). It measures attitudes on four subscales: empowerment, which essentially reflects choice and self-advocacy of people with intellectual disabilities; exclusion, which elicits beliefs about people with intellectual disabilities being excluded from society;

sheltering which encompasses beliefs about people with intellectual disabilities needing help and protection; and finally similarity, which measures whether a person views people with intellectual disabilities as similar to themselves.

The survey construction

Of the sections were required for this study, the survey began by presenting a vignette as part of the IDLS. This methodology is in line with other studies that have assessed knowledge and beliefs about a range of mental health problems amongst diverse cultural groups (Angermeyer et al., 2009; Jorm et al., 1997; Furnham & Chan, 2004). The vignette was unlabelled diagnostically and depicted an individual who meets diagnostic criteria for mild intellectual disability. After being presented with the vignette, participants were asked what they thought was going on with the person described in the vignette. Responses were categorised into one of twelve response categories, including intellectual disability and further assessed as to whether correct recognition (score=1) or incorrect recognition (score = 0) of the specified condition took place.

Participants were then asked to rate their agreement with 26 statements about possible causes of the difficulties stated within the vignette. Of these 22 load on four subscales: environment, adversity, biology, religion/fate and four items were added to the IDLS' original 22 items to study beliefs about potential religious causes, which load on one additional subscale: Sikh causes. Participants were then invited to rate their willingness to have social contact with someone like the person described in the vignette in seven situations of varying degrees of closeness. Scores were reversed and a mean calculated to give a social distance score, with a high score indicating a high desire for social distance. Participants were then presented with a 20-item version of the CLAS-MR, prior to the final section which ascertained participants'

socio-demographic information, including data on ethnicity, age, gender, educational attainments, religion, level of religious adherence and the amount of contact they have with people with intellectual disability.

Modifications to the CLAS-MR and the IDLS

For the purpose of this study, several adjustments were made to the IDLS and the CLAS-MR. The first modification was the name used in the vignette. In their analysis of the validity of the ILDS, Scior and Furnham (2011) suggested that validity may be increased if culturally matched names were given in each vignette. In light of this, a traditional Sikh name 'Manvir' replaced the Western name 'James' used with the white UK sample. Whilst considering the name, it was important to create a gender neutral name as Scior and Furnham (2011) also recognised that cultural rules may affect responses to social distance items, for example, the undesirability of social contact between unrelated males and females, rather than necessarily being a genuine indicator of stigma.

Secondly, for some of the original causal explanation items, words were added or language modified to suit the target audience. The word 'Waheguru', which is the Sikh description of God, was inserted alongside God in the causal item 'a test from God'. Extra items were also added including 'black magic/curse/jadoo tuna' (Punjabi description of black magic), 'lack of positive attitude', 'living selfishly/lack of sewa' (sewa is the Punjabi description of giving to charity), and 'lack of education about Sikhism'. The additional items were felt to reflect key tenets of the Sikh way of life, namely giving to charity, staying positive and ultimately focussing on others as opposed to oneself. The item on black magic was added as it was felt to reflect a popular belief amongst South Asian cultures generally (Hussain & Cochran, 2004).

For the social distance items to reduce undesirability of social contact with a

male in the evening, the time of day was altered. Two further items were added to this section in order to reflect the way in which practising Sikhs would be most likely to interact with individuals. These items were 'I would be happy to help guide someone like Manvir' and 'I would be happy to spend time at the Gurdwara with someone like Manvir'.

The CLAS-MR was used in its original form with three minor alterations: 1) the word 'mental retardation' was replaced with the term 'learning disabilities'; 2) a concise definition of the term 'learning disability' was added at the beginning of the CLAS-MR (BPS, 2008); 3) three items were added to the measure which have been found to discriminate between white British people and South Asians (Kenyon, 2008; Scior, 2010) and reflect common attitudes among the South Asian community.

Procedure

Participants were invited to complete a survey assessing attitudes towards people experiencing difficulties, either electronically online or in paper format. Prior to answering any questions, each participant was informed through the use of a cover sheet, that the survey was targeting the views of UK Sikhs. It was also made clear that the research was not looking for correct answers, only honest views. Participants were informed of the incentives and that the survey should take no longer than 15-20 minutes to complete. Stamped addressed envelopes were attached to paper copies of the survey to ensure that participants did not incur financial costs and to increase motivation to complete it.

Although Sikhs are known to converse in Hindi, Urdu and Farsi, Punjabi is their universal language. Therefore in order to ensure that the measure was accessible to all of the UK Sikh adult population, the IDLS was translated into Punjabi and was made available alongside the English version. The on-line surveys, in both English

and Punjabi, were available to the general public from September 2010 to May 2011.

Data Analysis

The data was analysed using SPSS, version 17. Prior to any statistical analysis being carried out the data was initially screened for normality and outliers. In some cases data were not normally distributed and non-parametric tests were used in these cases. The details of the analyses used are specified in relation to the research questions. For each question, comparisons were made to a matched white British sample and socio-demographic variables such as ethnicity, age, gender, education, religion, importance of religion, frequency of attendance at a place of worship and prior contact with intellectual disabilities, were also analysed. The Bonferroni correction was used to control the overall type 1 error rate following the use of multiple significance tests.

1) Are members of the Sikh community able to recognise symptoms of intellectual disability in response to an undiagnosed vignette?

To compare the two groups ability to recognise the symptoms presented in vignette as signs of possible intellectual disability, chi-squares were used. The same was also done for other causes identified by participants. To examine the ability of socio-demographic factors to predict recognition of intellectual disability, logistic regression was used.

2) What beliefs about the causes of intellectual disability are found in the UK Sikh community?

To compare the two group's levels of agreement about the causes of intellectual disability, univariate analysis of variance was used across three of the IDLS subscales. To compare the responses of the two groups on the 'religion/fate' subscale, a non-parametric test was used. For the two IDLS subscales with

significant differences across the groups, further item analysis took place using non-parametric analysis for the ‘religion/fate’ items and t-tests for the ‘environment’ items. To examine the Sikh responses to the fifth subscale completed by the Sikh sample only, mean scores and standard deviations were calculated. To examine the ability of socio-demographic factors to predict causal beliefs, multiple regressions were used.

3) What attitudes to the inclusion of people with intellectual disability are prevalent?

To assess the two groups’ attitudes towards the inclusion of people with intellectual disabilities, analysis of variance was used. As the data for the subscales ‘exclusion’ and ‘similarity’ were skewed, non-parametric analyses were used. To analyse group responses to the three items added to the CLAS-MR, mean and standard deviation scores were calculated. To examine the ability of socio-demographic factors on attitudes towards inclusion for both groups, multiple regressions were used.

4) What levels of social distance do the UK Sikh community desire towards people with intellectual disability?

In order to assess desire for social distance towards intellectual disability, t-tests were used, alongside mean and standard deviation scores, minus the extra two items added for the Sikh study. To examine the influences of socio-demographic factors on predictors of social desire for both groups, multiple regressions were used.

Ethical considerations

Ethical approval for the project was received from University College London Research Ethics Committee, project ID: 0960/001 (see Appendix 3). Participants were informed that it was their choice whether they were to take part in the survey or not and were free to withdraw at any time prior to sending the questionnaire. Apart from the prize draw section, which participants chose to complete, the questionnaire

was anonymous and contact details were immediately separated from responses on receipt to ensure confidentiality.

Results

This study aimed to investigate awareness, attitudes and beliefs about intellectual disability held by the UK Sikh community and to compare those findings with a white British sample. The results of the study are presented in seven sections: (1) data screening; (2) participants' characteristics; (3) inter-item reliability; (4) analyses of the ability to recognise intellectual disability; (5) analyses of casual beliefs regarding intellectual disability; (6) analyses of attitudes to inclusion; (7) analyses of desired social distance towards those with intellectual disabilities.

Data screening

The data were checked for assumptions of parametric data. Significant results ($p < .001$) on Levene's test highlighted that the assumption of homogeneity of variance was violated by the IDLS 'religion/fate' subscale and the CLAS-MR 'exclusion' and 'similarity' subscales. The distributions on these subscales were significantly skewed, 'similarity' negatively and 'exclusion' and 'religion/fate' positively, leading to a violation of the assumption of normally distributed data. Attempts were made to transform the data which proved to be ineffective. The subscale 'religion/fate' was understandably skewed as South Asian populations tend to attribute causes of intellectual disability to religion or fate, whereas the white British population are less likely to do so (Scior & Furnham, 2011). Analysis of the subscales with skewed distributions took place using non-parametric tests.

Participant characteristics

The samples were matched on age ($\chi^2 = 1.52$, $df = 2$, $p > .05$), gender ($\chi^2 = .06$, $df = 1$, $p > .05$) and educational attainment ($\chi^2 = .35$, $df = 1$, $p > .05$) and comprised of slightly

more females (55%) than males and participants ranged in age from 16 to 74, with a mean age of 29.90 ($S.D.$ = 11.42). Of the participants, 71% had obtained a degree and 48% had prior contact with someone with an intellectual disability, see Table 1.

Table 1

Demographics of participants (n=512)

| | Sikh <i>n</i> = 253 | | White British <i>n</i> = 259 | | Total | |
|----------------------|------------------------|------|---------------------------------|------|----------|------|
| | <i>n</i> | % | <i>n</i> | % | <i>n</i> | % |
| Gender | | | | | | |
| Male | 113 | 44.7 | 119 | 46.0 | 232 | 45.3 |
| Female | 139 | 54.9 | 140 | 54.0 | 279 | 54.5 |
| Missing | 1 | 0.40 | | | 1 | 0.2 |
| Age Group | | | | | | |
| 16 - 34 | 178 | 70.4 | 193 | 74.5 | 371 | 72.5 |
| 35 - 54 | 62 | 24.5 | 54 | 20.9 | 116 | 22.6 |
| 55 + | 13 | 5.1 | 10 | 3.8 | 23 | 4.5 |
| Missing | | | 2 | 0.8 | 2 | 0.4 |
| Education | | | | | | |
| Up to age 18 or less | 71 | 28.1 | 79 | 30.5 | 150 | 29.3 |
| Graduate | 182 | 71.9 | 180 | 69.5 | 362 | 70.7 |
| Prior contact | | | | | | |
| Yes | 80 | 31.6 | 163 | 62.9 | 243 | 47.5 |
| No | 89 | 35.2 | 74 | 28.6 | 163 | 31.8 |
| Missing | 84 | 33.2 | 22 | 8.5 | 106 | 20.7 |

Inter-item reliability

The extra four items added into the causal explanations section of the IDLS, for the purposes of this study, required inter-item reliability checks. The four items yielded a Cronbach's alpha of 0.67 indicating an acceptable fit. The values of the corrected item-total correlation coefficients ranged from 0.33 to 0.59, all indicating a positive relationship between each item and the total score of the combined items. The items were therefore considered appropriate to form a subscale, labelled 'Sikhcause'.

Three items were also added to the original CLAS-MR measure, which were felt to be particularly pertinent to the South Asian community (Scior & Furnham, 2011). The reliability analysis indicated a low Cronbach's alpha of 0.37. These

items were therefore not viewed as a subscale and were analysed individually. Two extra items added to the social distance subscale for the purposes of this study, yielded a Cronbach's alpha of 0.81, constituting a good fit and the corrected item-total coefficients were 0.69 for both items.

Recognition

In response to an unlabelled vignette, 36% of the Sikh participants were able to recognise symptoms of intellectual disability which was similar to that of white British participants, highlighting no significant difference between the groups ($\chi^2 = .19$, $df = 1$, $p > .05$). These findings were higher than Scior and Furnham's (2011) findings that 24% of participants were able to correctly identify symptoms of intellectual disability. Table 2 highlights the categorical responses given to the difficulties described in the unlabelled intellectual disability vignette by both the Sikh and white British participants. Overall there was no significant difference between the categorical attributions made by both groups about the difficulties depicted in the vignette ($\chi^2 = 7.20$, $df = 8$, $p > .05$).

Table 2

Categorised responses to intellectual disability vignette

| | Sikh <i>n</i> = 253 | | White British <i>n</i> = 259 | | Total | |
|------------------------------|------------------------|------|---------------------------------|------|----------|------|
| | <i>n</i> | % | <i>n</i> | % | <i>n</i> | % |
| Intellectual disability (ID) | 90 | 35.6 | 91 | 35.1 | 181 | 35.4 |
| Incorrect reference to ID | 13 | 5.1 | 17 | 6.6 | 30 | 5.9 |
| Reference to mental illness | 27 | 10.7 | 28 | 10.8 | 55 | 10.7 |
| Personal problems | 21 | 8.3 | 10 | 3.9 | 31 | 6.1 |
| Upbringing | 19 | 7.5 | 11 | 4.2 | 30 | 5.9 |
| Laziness/lack of motivation | 19 | 7.5 | 18 | 6.9 | 37 | 7.2 |
| Lacking direction in life | 33 | 13.0 | 40 | 15.4 | 73 | 14.3 |
| Don't know/other | 18 | 7.1 | 17 | 6.6 | 35 | 6.8 |
| Missing | 13 | 5.1 | 27 | 10.4 | 40 | 7.7 |

In order to assess the association between socio-demographic factors, namely ethnicity, age, gender, education, importance of religion in respondents' lives, frequency of religious worship and prior contact, on the ability to correctly recognise symptoms of intellectual disability, logistic regression was employed using a forced entry method, see Table 3.

The results indicate that gender, age and prior contact are significantly associated with recognition. In particular, females and those who have previously had contact with a person with an intellectual disability are more likely to recognise symptoms of intellectual disability. Regarding age, correct recognition was more likely with increased age of the participant. The results also highlight that a participant's ethnicity, in particular being Sikh or white British, does not independently predict recognition of symptoms of intellectual disability when the other socio-demographics are taken into account.

Table 3

Predictors of recognition of intellectual disability: results of logistic regression analyses

| | <i>B</i> | <i>B (SE)</i> | <i>e^B</i> | 95% Confidence interval | |
|------------------------|----------|---------------|----------------------|--------------------------------|--------------|
| | | | | <i>Lower</i> | <i>Upper</i> |
| Constant | -1.08*** | 0.42 | 0.08 | | |
| Ethnicity/Religion | -0.55 | 0.33 | 1.73 | 0.90 | 3.30 |
| Gender | -0.78** | 0.23 | 2.18 | 1.40 | 3.41 |
| Education | 0.33 | 0.24 | 0.72 | 0.44 | 1.15 |
| Age | 0.02* | 0.01 | 1.02 | 1.00 | 1.04 |
| Prior contact | -0.50* | 0.23 | 1.65 | 1.04 | 2.60 |
| Importance of religion | 0.03 | 0.07 | 1.03 | 0.90 | 1.17 |
| Religious practice | 0.10 | 0.13 | 1.10 | 0.82 | 1.43 |

Note: $R^2 = 5.33$ (Hosmer & Lemeshow), .07 (Cox & Snell), .09 (Nagelkerke). Model $\chi^2 (7) = 25.77$, $p < .01$

Ethnicity/Religion: 0=white British, 1=Sikh; Gender: 0=female, 1=male; Education: 0=to age 18 or less, 1=graduate; Prior contact: 0=yes; 1=no.

* $p < .05$; ** $p < .01$; *** $p < .001$

Causal beliefs

To investigate the extent to which the three normally distributed causal subscales were endorsed by Sikh and white British participants, univariate analyses of variance were carried out with a Bonferroni correction. Significant differences were found on the ‘environment’ subscale, see Table 4. Sikh participants were more likely to show agreement with the not normally distributed ‘religion/fate’ causes ($Mdn = 2.40$) than white British participants ($Mdn = 1.60$), $U = 20050.00$, $z = -7.67$, $p < .001$.

Table 4

IDLS causal explanation subscale: mean, standard deviation and ANOVA results

| | Sikh sample <i>M (SD)</i> | White British <i>M (SD)</i> | <i>f</i> | Effect Size <i>d</i> |
|-------------|-------------------------------------|---------------------------------------|----------|--------------------------------|
| Adversity | 3.53(1.22) | 3.52 (1.32) | .01 | 0.00 |
| Biomedical | 3.69 (1.35) | 3.65 (1.43) | .12 | 0.00 |
| Environment | 3.70 (1.25) | 3.41 (1.18) | 7.25* | 0.17 |
| Sikhcause | 3.34 (1.34) | | | |

Note: $p < .05$ *; $p < .001$ ***

As the samples differed significantly on the ‘environment’ and ‘religion/fate’ subscales further analyses were carried out of the constituent scale items. Non-parametric analysis for the ‘religion/fate’ subscale demonstrates that Sikhs significantly differed in their belief that intellectual disability may be ‘a test from God’, see Table 5.

Table 5

'Religion/Fate' subscale items: mean, standard deviation and t-test results

| | Sikh sample | White British | <i>U</i> |
|---------------------------------------|-------------|---------------|-------------|
| | <i>Mdn</i> | <i>Mdn</i> | |
| Religion/Fate | | | |
| Possession by spirits | 297.74 | 215.39 | 22115.50*** |
| Punishment for own past wrongdoings | 293.15 | 220.70 | 23491.50*** |
| Strong religious or spiritual beliefs | 280.13 | 232.52 | 26553.00*** |
| Punishment for parents' wrongdoings | 279.67 | 233.87 | 26902.00*** |
| A test from God / Waheguru | 332.70 | 181.37 | 13306.00*** |

Note: $p < .001$ ***

The item analysis on the environment subscale highlights significant differences on four of the items, see Table 6. It can be seen that Sikh participants particularly related the cause of disability to parenting style, family structure and a lack of contact with extended family. However, it should be noted that whilst these figures were higher than for white British participants, they were not the items which had the highest scores, but those which had the greatest difference in scores between the two groups.

Table 6

'Empowerment' subscale items: mean, standard deviation and t-test results

| | Sikh sample | White British | <i>t</i> | Effect Size <i>d</i> |
|-----------------------------------|----------------|----------------|----------|----------------------|
| | <i>M (S.D)</i> | <i>M (S.D)</i> | | |
| Environment | | | | |
| Overly spoilt as a child | 3.71 (2.03) | 3.18 (1.72) | -3.17** | 0.28 |
| Lack of daytime occupation | 4.30 (1.82) | 4.22 (1.78) | -0.50 | 0.04 |
| Very poor schooling | 4.32 (1.81) | 4.47 (1.65) | 0.99 | 0.09 |
| Being from a single-parent family | 3.20 (1.79) | 2.58 (1.64) | -4.13*** | 0.36 |
| Parents too lenient | 3.98 (1.92) | 3.55 (1.79) | -2.59* | 0.23 |
| Lack of an intimate relationship | 3.20 (1.84) | 3.36 (1.78) | 0.96 | 0.09 |
| Isolation from extended family | 3.20 (1.81) | 2.53 (1.53) | -4.52*** | 0.40 |

Note: $p < .05$ *; $p < .01$ **; $p < .001$ ***, p value adjusted using Bonferroni correction

Individual item analysis took place for the subscale 'Sikhcause' as there was no comparable data to use from the white British participants. The item 'lack of positive attitude' had the highest level of agreement ($M = 4.38$, $S.D. = 1.97$), followed by the item 'lack of education about Sikhism' ($M = 3.27$, $S.D. = 2.01$). The item rated second least was 'living selfishly' ($M = 2.88$, $S.D. = 1.86$) and the item rated the least was the item 'black magic/curse/jadoo tuna' ($M = 2.35$, $S.D. = 1.88$).

Multiple regressions were used to assess the influence of socio-demographic factors on the causal explanation subscales, see Table 7. It can be seen that age and gender were significant predictors. Specifically, as the age of the participants increased, agreement with 'adversity', 'religion/fate' and 'environment' related variables as a potential cause of intellectual disability decreased, while agreement with biomedical causes increased. Males were less likely to agree with biomedical causality, and more likely to agree with environmental causality than females. Ethnicity only predicted belief in 'religion/fate' related causes; Sikhs were more likely to be in agreement than white British participants. Notably, all these factors together only explained between 5% and 20% of the variance in responses.

Table 7

Predictors of IDLS causal explanations: results of multiple regression analyses

| | | | | 95% confidence interval | |
|------------------------|----------|---------------|---------|-------------------------|--------------|
| | <i>B</i> | <i>B (SE)</i> | β | <i>Lower</i> | <i>Upper</i> |
| Adversity | | | | | |
| Constant | 3.94*** | 0.24 | | 3.48 | 4.40 |
| Ethnicity | -0.06 | 0.19 | -.02 | -0.43 | 0.30 |
| Gender | 0.07 | 0.13 | .03 | -0.17 | 0.33 |
| Education | 0.13 | 0.14 | .05 | -0.14 | 0.40 |
| Age | -0.02*** | 0.01 | -.21 | -0.04 | -0.01 |
| Prior contact | 0.02 | 0.13 | .01 | -0.24 | 0.28 |
| Importance of religion | 0.01 | 0.04 | .02 | -0.07 | 0.08 |
| Religious practice | 0.06 | 0.08 | .07 | -0.09 | -0.21 |
| Biomedical | | | | | |
| Constant | 3.05*** | 0.26 | | 2.55 | 3.55 |
| Ethnicity | -0.39 | 0.20 | -.14 | -0.79 | 0.00 |
| Gender | -0.40** | 0.14 | -.14 | -0.67 | -0.13 |
| Education | -0.02 | 0.15 | -.01 | -0.31 | 0.27 |
| Age | 0.01* | 0.01 | .11 | 0.00 | 0.03 |
| Prior contact | -0.04 | 0.14 | -.02 | -0.32 | 0.24 |
| Importance of religion | 0.05 | 0.04 | .12 | -0.03 | 0.13 |
| Religious practice | 0.13 | 0.08 | .15 | -0.03 | 0.30 |
| Fate | | | | | |
| Constant | 1.83*** | 0.20 | | 1.44 | 2.22 |
| Ethnicity | 0.53** | 0.16 | .23 | 0.22 | 0.83 |
| Gender | 0.11 | 0.11 | .05 | -0.10 | 0.31 |
| Education | -0.17 | 0.11 | -.07 | -0.39 | 0.06 |
| Age | -0.01* | 0.01 | -.12 | -0.02 | -0.00 |
| Prior contact | 0.08 | 0.11 | .03 | -0.14 | 0.29 |
| Importance of religion | 0.05 | 0.03 | .14 | -0.01 | 0.11 |
| Religious practice | 0.09 | 0.06 | .13 | -0.03 | 0.22 |
| Environment | | | | | |
| Constant | 3.60*** | 0.22 | | 3.16 | 4.03 |
| Ethnicity | 0.21 | 0.17 | .09 | -0.13 | 0.55 |
| Gender | 0.49*** | 0.12 | .20 | 0.26 | 0.72 |
| Education | -0.13 | 0.13 | -.05 | -0.38 | 0.12 |
| Age | -0.02* | 0.01 | -.15 | -0.03 | -0.01 |
| Prior contact | 0.13 | 0.13 | .05 | -0.11 | 0.38 |
| Importance of religion | -0.01 | 0.04 | -.01 | -0.08 | 0.06 |
| Religious practice | 0.06 | 0.07 | .08 | -0.08 | 0.02 |

Note: Adversity $R^2 = 0.05$, $p < .01$, $f^2 = 0.05$; Biomedical $R^2 = 0.07$, $p < .001$, $f^2 = 0.08$; Fate $R^2 = 0.20$, $p < .001$, $f^2 = 0.03$, Environment $R^2 = 0.08$, $p < .001$, $f^2 = 0.09$; * $p < .05$, ** $p < .01$, *** $p < .001$; Ethnicity: 0=white British, 1=Sikh; Gender: 0=female, 1=male; Education: 0=to age 18 or less, 1=graduate; Prior contact: 0=yes; 1=no.

Analysis of the influence of socio-demographic factors on the ‘Sikhcause’ subscale suggests higher endorsement by Sikh males and non-graduates, see Table 8. The factors considered explained only 12% of the variance.

Table 8

Predictors of IDLS causal explanation Sikhcause: results of multiple regression analyses

| | Intellectual Disability | | | 95% confidence interval | |
|------------------------|-------------------------|---------------|---------|-------------------------|--------------|
| | <i>B</i> | <i>B (SE)</i> | β | <i>Lower</i> | <i>Upper</i> |
| Constant | 2.36** | 0.57 | | 1.23 | 3.49 |
| Gender | 0.46* | 0.21 | .17 | 0.05 | 0.87 |
| Education | -0.48* | 0.23 | -.16 | -0.92 | -0.03 |
| Age | -0.01 | 0.01 | -.07 | -0.03 | 0.01 |
| Prior contact | 0.18 | 0.20 | .07 | -0.22 | 0.58 |
| Importance of religion | 0.07 | 0.06 | .10 | -0.06 | 0.20 |
| Religious practice | 0.19 | 0.13 | .14 | -0.06 | 0.43 |

Note: $R^2 = 0.12$, $p < .01$, $f^2 = 0.14$; * $p < .05$, ** $p < .001$

Ethnicity: 0=white British, 1=Sikh; Gender: 0=female, 1=male; Education: 0=to age 18 or less, 1=graduate; Prior contact: 0=yes; 1=no.

Attitudes to inclusion

Analysis of variance was used to analyse the attitudes which existed towards the inclusion of people with intellectual disabilities by the Sikh and white British samples. These were measured by the CLAS-MR subscales and the additional items used in this study, see Table 9. Analysis of the subscales with skewed data took place using non-parametric tests

Table 9

CLAS-MR inclusion subscales: mean, standard deviation and t-test results

| | Sikh | White British | Effect Size | |
|-------------|---------------|---------------|-------------|----------|
| | <i>M (SD)</i> | <i>M (SD)</i> | <i>f</i> | <i>d</i> |
| Empowerment | 4.19 (0.87) | 4.50 (0.82) | 16.89*** | 0.36 |
| Sheltering | 3.49 (0.87) | 3.25 (0.82) | 10.21** | 0.29 |
| CLAS-Sikh | 2.45 (0.93) | | | |

Note: * $p < .05$; ** $p < .01$; *** $p < .001$

The results highlight significant differences across two of the three subscales. For the subscale ‘empowerment’ subscale Sikh participants had significantly lower levels of agreement than white British participants. However, for the ‘sheltering’ subscale they had significantly higher levels of agreement than white British participants, both with small effect sizes. Rates of agreement on the ‘exclusion’ subscale between Sikh participants ($Mdn = 1.50$) and white British participants ($Mdn = 1.25$) did not differ significantly, $U = 31913.00$, $z = -0.52$, $p > .05$. Sikh participants ($Mdn = 5.25$) were less likely to agree to items on the similarity subscale than white British participants ($Mdn = 5.75$), $U = 22346.50$, $z = -6.36$, $p < .001$.

Item analysis of the extra three CLAS-MR items highlighted participants as least likely to disagree with the statement ‘parents should bear the main responsibility for children with learning disabilities’ ($M=3.08$, $S.D=1.33$). Sikh participants clearly disagreed with the other items though: ‘having a person with a learning disability in a family may damage the marriage prospects of siblings’ ($M=1.71$, $S.D=1.67$) and ‘families should hide their relatives with learning disabilities rather than draw attention to the learning disability through services’ ($M=1.14$, $S.D=1.67$). In order to assess the influence of socio-demographic factors on CLAS-MR scores, multiple regression analyses were performed, see Table 10.

Table 10

Predictors of CLAS-MR inclusion subscales: results of multiple regression analyses

| | <i>B</i> | <i>B (SE)</i> | β | 95% confidence interval | |
|------------------------|----------|---------------|---------|-------------------------|--------------|
| | | | | <i>Lower</i> | <i>Upper</i> |
| Empowerment | | | | | |
| Constant | 5.10*** | 0.15 | | 4.81 | 5.34 |
| Ethnicity | -0.20 | 0.12 | -.12 | -0.43 | 0.04 |
| Gender | -0.17* | 0.08 | -.10 | -0.33 | -0.01 |
| Education | 0.05 | 0.09 | .03 | -0.12 | 0.22 |
| Age | -0.01* | 0.00 | -.16 | -0.02 | -0.01 |
| Prior contact | -0.20* | 0.08 | -.12 | -0.36 | -0.03 |
| Importance of religion | 0.05* | 0.02 | .20 | 0.01 | 0.10 |
| Religious practice | -0.13** | 0.05 | -.25 | -0.23 | -0.04 |
| Exclusion | | | | | |
| Constant | 1.49*** | 0.16 | | 1.18 | 1.81 |
| Ethnicity | 0.15 | 0.13 | .09 | -0.10 | 0.39 |
| Gender | 0.25** | 0.09 | .15 | 0.09 | 0.42 |
| Education | -0.20* | 0.09 | -.11 | -0.38 | 0.02 |
| Age | 0.01 | 0.01 | .03 | -0.01 | 0.01 |
| Prior contact | 0.17 | 0.09 | .10 | -0.01 | 0.34 |
| Importance of religion | -0.03 | 0.03 | -.09 | -0.07 | 0.03 |
| Religious practice | 0.04 | 0.05 | .07 | -0.06 | 0.14 |
| Sheltering | | | | | |
| Constant | 2.91*** | 0.16 | | 2.61 | 3.29 |
| Ethnicity | 0.16 | 0.12 | .10 | -0.08 | 0.40 |
| Gender | -0.06 | 0.08 | -.04 | -0.23 | 0.10 |
| Education | 0.01 | 0.09 | .01 | -0.17 | 0.18 |
| Age | 0.01* | 0.00 | .11 | 0.00 | 0.01 |
| Prior contact | 0.04 | 0.09 | .02 | -0.13 | 0.21 |
| Importance of religion | 0.00 | 0.03 | .01 | -0.05 | 0.05 |
| Religious practice | 0.05 | 0.05 | .10 | -0.05 | 0.15 |
| Similarity | | | | | |
| Constant | 5.50*** | 0.14 | | 5.22 | 5.79 |
| Ethnicity | -0.40*** | 0.11 | .25 | -0.63 | -0.18 |
| Gender | -0.17* | 0.08 | -.10 | -0.32 | -0.02 |
| Education | 0.25** | 0.08 | .14 | 0.08 | 0.41 |
| Age | 0.00 | 0.00 | -.00 | -0.01 | 0.01 |
| Prior contact | -0.29* | 0.08 | -.13 | -0.38 | -0.06 |
| Importance of religion | 0.01 | 0.02 | .05 | -0.03 | 0.06 |
| Religious practice | -0.03 | 0.05 | -.06 | -0.12 | 0.06 |

Note: Environment $R^2 = 0.10$, $p < .001$, $f^2 = 0.11$; Exclusion $R^2 = 0.05$, $p < .05$, $f^2 = 0.05$; Sheltering $R^2 = 0.06$, $p < .01$, $f^2 = 0.06$; Similarity $R^2 = 0.13$, $p < .001$, $f^2 = 0.15$; * $p < .05$, ** $p < .01$, *** $p < .001$

Ethnicity: 0=white British, 1=Sikh; Gender: 0=female, 1=male; Education: 0=to age 18 or less, 1=graduate; Prior contact: 0=yes; 1=no.

Females, younger participants and those with prior contact were more likely to endorse the 'empowerment' subscale. The association between religion and empowerment appears to be a mixed one in that those who placed increased importance on religion were more likely to endorse this subscale, yet increased attendance at a place of worship had the opposite effect. Males were more likely to endorse 'exclusion', as well as those who were non-graduates. Regarding sheltering, as the age of participants increased, so did their level of agreement with the 'sheltering' subscale. Finally, white British participants significantly endorsed the 'similarity' subscale over the Sikh participants. Females, graduates and those with previous contact also significantly endorsed this subscale. Of note, the variables examined explained only between 5% and 13% of the variance in inclusion attitudes.

Desire for social distance

Participants' desire for social distance was examined using the five IDLS items and the two items added for the purposes of this study, with higher scores indicating a greater desire for social distance. On comparison of the five original items for which the scoring was reversed, the Sikh sample had a slightly lower overall score, with a mean of 3.54 ($S.D = 1.48$), than the white British sample who had a mean of 3.70 ($S.D = 1.46$). Independent samples t-test with a Bonferroni correction revealed that there was no overall significant difference between the two groups, $t(510) = 1.25$, $p > .05$. Table 11 displays the results for individual items revealing significant results on three items, all indicating a greater desire for social contact by white British participants. The two added items suggest that Sikhs required less social distance from a person with intellectual disability when in the Gurdwara or when in the role of a helper.

Table 11

Social distance items: mean, standard deviation and t-test results

| | Sikh | White British | <i>t</i> | Effect size <i>d</i> |
|----------------------------|---------------|---------------|----------|----------------------|
| | <i>M (SD)</i> | <i>M (SD)</i> | | |
| Move next door | 3.23 (1.77) | 2.98 (1.62) | -1.63 | 0.15 |
| Socialise | 3.32 (1.69) | 3.63 (1.72) | 2.00* | 0.18 |
| Work closely | 3.23 (1.76) | 3.92 (2.18) | 0.53** | 0.35 |
| Make friends | 3.21(1.63) | 3.61 (1.72) | 2.74** | 0.24 |
| Marry into my family | 4.70 (1.80) | 4.58 (1.72) | -0.72 | 0.12 |
| Help guide | 2.24 (1.33) | | | |
| Spend time at the Gurdwara | 2.49 (1.60) | | | |

Note: * $p < .05$, ** $p < .01$

The influence of socio-demographic factors upon social distance were examined using a multiple regression, see Table 12.

Table 12

Predictors of social distance: results of multiple regression analyses

| | <i>B</i> | <i>B (SE)</i> | β | 95% confidence interval | |
|------------------------|----------|---------------|---------|-------------------------|-------|
| | | | | Lower | Upper |
| Constant | 4.29*** | .24 | | 3.81 | 4.77 |
| Ethnicity | 0.26 | .20 | .08 | -0.14 | 0.66 |
| Gender | 0.23 | .14 | .08 | -0.04 | 0.51 |
| Education | -0.11 | .15 | .04 | -0.41 | 0.19 |
| Age | -0.01* | .01 | -.10 | -0.03 | 0.00 |
| Prior contact | 0.33* | .14 | .13 | 0.05 | 0.62 |
| Importance of religion | -0.13*** | .03 | -.28 | -0.19 | -0.07 |

Note: $R^2 = 0.12$, $p = <.001$, $f^2 0.14$

Ethnicity: 0=white British, 1=Sikh; Gender: 0=female, 1=male; Education: 0=to age 18 or less, 1=graduate; Prior contact: 0=yes; 1=no.

It can be seen that as the age of participants increased their desire for social distance decreased. People who had not previously had contact with a person with an intellectual disability were also more likely to endorse social distance. Finally, as the level of religious importance increased, participants were less likely to endorse social distance.

Discussion

Summary of findings

This study set out to assess the awareness, attitudes and beliefs regarding intellectual disability of a UK Sikh sample and to compare those findings to a white British sample. The findings indicated that overall there were very few significant differences between the responses from both groups, which is in line with previous research (Coles & Scior, in press).

Ethnicity, the primary area of interest, was found to be a significant factor in relation to only one subscale, the causal explanation ‘religion/fate’. Individual item analysis of this subscale highlighted significant differences on all of the ‘religion/fate’ subscale items indicating that Sikhs were more likely to endorse religion or fate as a cause of intellectual disability than white British participants. Sikh participants were also found to be less likely to endorse inclusion as opposed to white British participants, but with increased levels of religious importance were less likely to endorse social distance, similar to white British participants.

Recognition of intellectual disability

The assessment of participants’ ability to recognise symptoms of intellectual disability was made through the categorisation of free-text responses to an unlabelled vignette. The responses indicated that a small number of participants were able to recognise intellectual disability symptoms, regardless of ethnicity. Being female, increased age and previous contact were associated with correct recognition of intellectual disability.

Although slightly higher than those of Scior and Furnhams findings, these findings suggest that in reality there is only a small likelihood that a Sikh or white British lay person would recognise symptoms of mild intellectual disability. This is

of interest in relation to Raghavan et al.'s (2009) observation that lower uptake of intellectual services by South Asians is related to a range of factors including lower awareness of intellectual disability. Although the Sikh sample was unrepresentative of the general population, in terms of being relatively highly educated, the findings do seem to indicate that, at least for the Sikh community, lower awareness of intellectual disability may not be a factor explaining poor uptake of services, given that it is not significantly different from the white British community.

Causal beliefs

The analysis of the four causal explanation subscales highlighted significant differences on 'religion/fate' and 'environment' between the samples. The item 'possession by spirits' from the IDLS 'religion/fate' subscale received very little endorsement across both groups. Although this was important in the IDLS as constructed by Scior and Furnham (2011), who also examine beliefs towards schizophrenia, this item appears irrelevant in future research targeting only responses to intellectual disability.

The overall difference on the 'religion/fate' subscale was anticipated as Scior and Furnham (2011) highlighted that South Asian populations were much more likely to attribute the cause of intellectual disability to fate related causes than white British groups. In their study in India, Madhavan et al., (1990) also highlight a belief in 'God's will' as the most likely cause. However, the highest mean score was three (disagree somewhat) in the Sikh sample, indicating overall disagreement with religion or fate as a cause of intellectual disability by both groups. When considering environmental causes, Sikh participants were more likely to attribute difficulties to family make-up as opposed to schooling or relationship issues.

It is clear from the ‘Sikhcause’ items that neither sample attributed the difficulties described to ‘possession by spirits’ or ‘black magic/curse/jadoo tuna’, despite findings from previous research which has indicated that South Asian populations ascribe belief of the cause of intellectual disability to religion or fate (Murthy, Wig & Dhir, 1980) or a curse from God (Zaman et al., 1987).

Discrepancies in the findings may relate to the fact that both studies were carried out in South Asia, over twenty years previously. Ideas of fate, religion and God may have been deeply embedded within those cultures to a much higher level than in modern day South Asian families living within the UK. The current findings suggest that Sikhs living in the UK may have adapted their views on the influence of fate, religion or God as a cause of intellectual disability to favour environmental and biomedical explanations, whilst at the same time endorsing the belief, but only slightly more than white British lay people.

The significant socio-demographic factors associated with causal explanations for intellectual disability amongst both samples were primarily age, followed by gender with ethnicity being a significant predictor for only one subscale. The older a participant was, the more likely they were to agree with biomedical causes of intellectual disability and less likely to agree with ‘adversity’, ‘environment’ and ‘religion/fate’ related causes. This may indicate that a desire for older participants to believe in more concrete, scientifically understandable explanations of intellectual disability such as genetic factors than younger participants. Although it may be intuitive to expect the opposite, this finding may be related to a number of factors.

Older participants may have for example over time had more exposure to healthcare services than younger participants and as a result may be more likely to

adhere to a medical model. Older participants, particularly those from the West, may also have been exposed to biological explanations of intellectual disability from a younger age and as a result be less familiar with a social model of intellectual disability. Furthermore, for Sikh older participants, the lack of reference to intellectual disability within Sikhism, in particular its religious texts, may defer explanations away from religiosity or fate.

There was also a gender difference in belief of biomedical and environmental causes, with males displaying more agreement with environmental causality. This may be related to previous research which highlights the tendency for mothers in particular to blame themselves for the cause of intellectual disability (Edwardraj et al., 2010), and others to the peri-natal period (Zaman et al., 1987; Bywaters et al., 2003).

Attitudes to inclusion

Significant differences existed between the Sikh and white British samples on all of the CLAS-MR subscales minus ‘exclusion’, where both groups disagreed with the exclusion of people with intellectual disabilities from community life. Sikhs agreed to the need to shelter people with intellectual disabilities more so than white British participants, which may be related to South Asian ideas of sheltering those with intellectual disabilities from communities (Croot et al., 2008; Islam, 2008) in order to prevent stigma from being attached to the entire family. Sikhs agreed less with ‘empowerment’ and significantly less with the ‘similarity’ subscale items. The scores on the items added to the CLAS-MR indicate little agreement with the idea of hiding a family member with an intellectual disability and that such an individual may damage the marriage prospects of siblings. This may indicate that the higher level of agreement with sheltering by Sikhs is not related to averting negative effects.

It may instead relate to a desire to protect individuals with intellectual disabilities, for example, from negative encounters with community members who hold negative stereotypical ideas.

In addition to age and gender, prior contact with a person with an intellectual disability was found to be significantly associated with agreement to empowerment. However, the relationship between religion and empowerment appears to be complex as those who attended a place of worship were less likely to endorse this subscale versus those who placed more emphasis on the importance of religion. Whilst it may be assumed that both of the items on religion would lead to a similar levels of agreement on empowerment, there appears to be a need for caution when examining their relationship especially as a similar, albeit, non-significant mixed pattern also occurred in relation to the ‘exclusion’ and ‘similarity’ subscales. It is possible that in this case, the questions were assessing two independent, non-associated levels of religious practice.

Males and non-graduates were found to significantly endorse the ‘exclusion’ subscale, whereas females and graduates were found to endorse the ‘similarity’ subscale. On the ‘sheltering’ subscale, age was the only associated socio-demographic. When combined with the ‘exclusion’ subscale findings, it can be seen that no one variable was significantly found to be associated with the more negative attitudes towards inclusion.

Desire for social distance

Sikh participants were found to be less willing to work closely and make friends with a person with an intellectual disability than white British participants. The two items added to the scale revealed that Sikh participants were in much more agreement about helping guide, and spending time at the Gurdwara, with a person with an

intellectual disability. This indicates more willingness when in a place of worship and when the interaction role was one of support giver. Overall, the social distance scales were designed to tap into social scenarios of increasing intimacy, which is reflected at least to some extent in the white British sample's responses. However the same does not hold for Sikhs who show similar responses to the different scenarios, with the exception of marrying into the family.

Analysis of socio-demographic factors highlighted that as participants' age and previous contact increased, the desire for social distance decreased. Increased importance place on religion was associated with a lower desire for social distance for both white British and Sikh participants. As social distance is an important indicator of stigma, the similarity across both groups for this finding is of particular interest. Previous research has suggested that South Asians are more likely to hold stigmatising beliefs about intellectual disability. South Asians have for example been found to believe that intellectual disability results from possessions by spirits (Hatton et al., 2003) or punishment for past sins (Hubert, 2006). Although this finding may indicate that the Sikh sample hold less stigmatising beliefs than anticipated, other explanations must also be considered.

First, the previous studies cited all focused on South Asian individuals in the UK with intellectual disability and their families. It is possible that these families may be particularly sensitive to any potential signs of stigma, due to the greater importance placed on community cohesion within Asian culture. As Scior (in press) notes, to date research has not examined the general public's responses to intellectual disability within a South Asian context. Thus it is conceivable that stigmatising

attitudes may be held by a small number of South Asian individuals rather than the broader community.

Another influence on the sample may be to do with acculturation, whereby Sikh participants may have adopted Western views and as a result the findings were more in line with white British participants. The findings in the present study may simply highlight beliefs of a previously under-researched South Asian population whose beliefs may differ to those of other South Asian groups. The findings may relate directly to Sikhism's emphasis on helping others. However, most other religious doctrines also lay emphasise on this. In light of this, perhaps the current study assessed level of religious importance in a unique way compared to other studies on ethnicity and intellectual disability.

Socio-demographic variables

Of the socio-demographic factors, age was found to be significantly associated with eight of the subscales, gender with seven, prior contact with four and education with three subscales. Level of religious importance was significantly associated with two subscales and, finally, attendance at a place of worship with one.

Previous research has shown that gender, age and education are associated with attitudes towards individuals with intellectual disabilities. Positive attitudes are more commonly expressed by females, younger people and those with high educational attainments (Akrami et al., 2006; Antonak et al., 1995; Burge et al., 2007; Esterle et al., 2008; MacDonald & MacIntyre, 1999; Ouimet & De Man, 1998). However the effect of gender, in particular, has also been found to be inconsistent (Hudson-Allez & Barrett, 1996; Karellou, 2003; Nagata, 2007; Ouellette-Kuntz et al., 2010; Yazbeck et al., 2004). In this current study gender has certainly been a significant factor; however, there was no clear dichotomy between

males and females in terms of positive and negative attitudes. Prior contact was however associated with more positive attitudes across the subscales, which has also been shown in previous research (Antonak & Harth, 1994; Antonak et al., 1995; Bethwick & Matthews, 1994; Horner-Johnson et al., 2002; Yazbeck et al., 2004).

Significance

When analysing the mean scores between groups on the subscales item analysis on the individual items took place in order to understand significant differences in more depth. On several occasions, significant differences were found to be present. However, when looking at the overall mean scores, a similar rating score would be present across both groups, indicating the same level of general agreement or disagreement on an item. This draws attention to a gap between statistical and clinical significance. Whilst statistically the findings are of interest, the mean scores indicate similarity between responses, and therefore clinically are of less importance. This highlights that on face value only, there were no large differences between the samples in many of the items and the subscales. Although this was raised in the empirical paper, it will be an important factor to consider prior to disseminating the results of the survey.

Clinical Implications

The findings from this study generally indicated similarity between the groups. Given that overall the groups were both highly educated and tended to be predominantly middle aged, it is clear that caution must be used when interpreting the findings. The study draws attention to a previously non researched group: UK Sikhs and an overview in the introduction provides a basic insight into Sikhism which can be used by clinicians and researchers in order to become more familiar with the way of life and history of Sikhs. Secondly, the results of the study highlight that on the whole highly educated Sikhs living in the UK have similar views

regarding intellectual disability as their white British counterparts. While the similar rates of recognition of intellectual disability suggest similar understanding at least among more educated lay people. The fact that Sikhs were somewhat less likely to endorse inclusion though suggests a need for more positive messages emphasising the benefits of social inclusion for individuals with intellectual disabilities, their families but also the wider community.

The present findings suggest that stigma associated with intellectual disability may be less of an issue among the Sikh community than suggested in the literature on South Asians in the UK generally (Hatton et al., 2003; Hubert, 2006). A finding that should be of interest to clinicians is that increased levels of religious importance appear to be associated with reduced social distance. Clinicians may be able to tentatively explore levels of stigma experienced by family members, caregivers or care staff towards people with intellectual disabilities, by assessing their levels of religious importance. This may in turn aid therapeutic work either directly with clients and their care staff, or indirectly through consultative practice. Stigma reducing and awareness raising campaigns may also benefit from targeting members of communities who are likely to rate religion as important. In this way, smaller, hard to reach communities may be accessed with reduced difficulty and act as a focal point from which to work.

Limitations of this study

Whilst this study examined awareness, attitudes and beliefs regarding intellectual disability amongst an un-researched religious South Asian group in a way that was considered to be culturally appropriate, several limitations should be noted. Of primary importance is the sample which was collected. Although this study aimed to draw attention to UK Sikhs, caution should be exercised when drawing inferences

from the findings. Although the sample size in this study was fairly large, the samples were convenience samples. The fact that participants on the whole were highly educated indicates that the findings may not be representative of the general UK population.

Secondly, using two criteria for recruitment, namely ethnicity and religion, had limitations. First, the Sikh sample was somewhat mixed as eight of 253 participants identified themselves as Sikh, but not South Asian unlike the vast majority of the Sikh population in the UK. For the white British sample, religious self-categorisation was also flawed. In the Western population, many individuals may describe themselves as 'Christian', purely for reasons such as having been christened in childhood or having attended church at some point in the past, while others in a similar position may define themselves as agnostic or non-religious. Hence this group was treated largely as a homogenous group due to their shared ethnic background. Furthermore for the purposes of analyses other indicators of religion were used, namely level of religious importance and attendance at a place of worship, as these were deemed more useful.

The attempt to focus on differences in attitudes and beliefs on the basis of religious affiliation may have been limited. Instead, understanding such differences in the context of level of religious adherence and importance of religion in individuals' lives appears to have been more informative.

In relation to the methodology, of primary concern is the use of the unlabelled vignette. Although this provided important information in order to assess correct recognition of intellectual disability symptoms, the participants' responses to the causal explanation and social distance items were a reflection of their attribution to the difficulties described rather than their beliefs about intellectual disability. As

the definition of intellectual disability was given prior to the CLAS-MR inclusion items, it may have been logical to have moved the definition to after the vignette was presented in order to gather responses which were specific to intellectual disability. However, although the online surveys could have prevented participants from answering previous items in the survey, a paper copy would not have been able to do so. The structure used was with hindsight the most appropriate for the paper copy.

Also in relation to the survey used, the IDLS was deemed the most appropriate measure for this study alongside the CLAS-MR. Whilst they have been found to have sound psychometric properties and to have good reliability cross culturally, it is important to note the possible impact of the use of such measures, which are constructed based on formal, agreed upon definitions of intellectual disability. A significant effort was made to incorporate and explore explanations of intellectual disability that may not be in line with a medical or expert led model. It is hoped that due to this, participants believing in more spiritual or religious explanations of intellectual disability may have felt able to express such beliefs. However the surveys used may have an inevitable Western, scientifically generated feel to them for participants. In this way, certain explanations of intellectual disability may be deemed as wiser or more educated and therefore ‘correct’ compared to other explanations. This unintentional privileging of certain explanations may be less apparent in other research methodologies such as focus groups or interviews for example.

A further criticism of the method used relates to generalisability. Responses to items gathered in a brief questionnaire may not accurately reflect views held towards a person with intellectual disability. This may be even more so for those who have not had any previous contact with a person with an intellectual disability.

Finally, this survey assessed a religious group within which there is a clear group of people (amritdharis) who were religiously adherent, but failed to take into account this group's responses. Although knowledge of a participants' level of religious importance and attendance at a place of worship may have highlighted interesting results, further analysis regarding the amritdhari group and whether their views differed to non-amritdharis may have demonstrated further significant responses.

Future research

This research has highlighted a number of potential avenues for further research. Although interesting results were drawn from the comparison of Sikhs to a white British sample, a number of questions remain. Future research into South Asian groups may also benefit from specifically analysing level of religious adherence as defined by the religion, rather than attempts to understand religious adherence through the use of a few general terms applicable to the larger sample. It is unclear whether a difference exists between amritdhari and non-amritdhari Sikhs, of whether responses would differ from participants who were older and whose primary language was Punjabi. Also, level of religious importance in relation to stigma warrants further investigation across other populations, prior to drawing conclusions about the Sikh sample.

Future research may also benefit from an altered methodology, consisting of a labelled vignette, or clarification of the term intellectual disability prior to obtaining responses on causes and social distance. Other methodologies such as exposure to a short film regarding intellectual disability followed by the completion of the IDLS may produce responses which are more accurate and genuine. Scior and Furnham (2011) compare attitudes towards intellectual disability to attitudes towards schizophrenia. Further research could use the same or a modified approach to also

understand Sikh attitudes towards mental health issues, and then compare those findings to the findings from the present study. This would allow for an interesting comparison to be made of how Sikhs view mental health problems compared to intellectual disability. Finally, mental health studies have found that emotional reactions are important mediators between attributions and stigma (Angermeyer, Holzinger & Matschinger, 2010). Future research would benefit from the incorporation of emotional reactions upon attitudes towards intellectual disability amongst south Asian groups. Such variables could then also be compared to level of religious adherence to understand relationships.

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Part 3: Critical Appraisal

Critical appraisal of a study on public awareness, attitudes and beliefs about intellectual disability: A Sikh perspective

Introduction

At the heart of this thesis was the goal of exploring the views held towards intellectual disability by members of a relatively under-researched group, UK Sikhs. Given the dearth of literature on the Sikh population in any field, the literature review aimed to investigate the conceptualisation of intellectual disability from a more global South Asian perspective. The empirical study sought to analyse awareness, causal beliefs and attitudes towards inclusion and social distance held by the UK Sikh community and to compare those to a white British sample. The aim of this critical appraisal is to reflect on the whole research process by drawing attention to the different stages of the study and to consider some limitations in more depth.

Reflections on the literature review

The literature review was undertaken to gather beliefs and information about needs and existing initiatives concerning intellectual disability from a South Asian perspective. In order to gather as much relevant material as possible the scope of the search was broadened to include a slightly wider geographical area as opposed to some narrower definitions of South Asia that include only Pakistan, India, Bangladesh and Sri Lanka. Secondly, the review did not only focus on South Asia as defined by geographical location, but also incorporated views of South Asians living in non-South Asian countries. Despite using the broader search criteria, attempts to understand the topic at hand were made primarily in the UK, presumably due to its multicultural status and large South Asian population and secondly in India, one of the most advancing South Asian countries. In retrospect, this suggests that extending the search criteria was unnecessary.

Whilst reviewing the literature, a dilemma was encountered regarding the approach used. Although the rationale for gathering as much relevant information was clear, at times I questioned the appropriateness of drawing inferences from literature originating from extremely different populations. This was particularly relevant when reviewing studies originating from the UK. It is clear that deprivation, poor standards of living and numerous barriers to accessing services exist for South Asians residing in the UK. It is also apparent that South Asian carers of people with intellectual disabilities are surrounded by similar issues of blame and lack of support. However, when reviewing studies about people living in rural areas in India who had no access to services, as opposed to limited access and whose priority it was to find food for their families, it felt as though the literature was attempting to be all-encompassing. As a result my thoughts were drawn to how the review could have either focussed on studies which had taken place in South Asia or on studies which have taken place on South Asians in the UK. The former may have focussed particularly on the effect of poverty and intellectual disability but would have been limited in terms of its relevance to South Asians living in the UK. The latter may have incorporated more issues relevant to the UK South Asian population such as pathways to care and service utilisation, but may have risked reiterating well-known, existing debates within the intellectual disability arena such as prevalence rates within the UK (Emerson et al., 1997; McGrother et al., 2002).

A further dilemma was experienced in regards to research carried out in India which referred generally to the notion of implementing Western based ideologies within a non-Western country. In reviewing papers on service implementation, it was easy to get drawn in to ideas on service provision based on methods tested in non-South Asian countries. However, whether ideas regarding treatment and change

can be successfully translated from one country to another country is questionable. Whilst modern, urban living individuals may be able to acclimatise to Western models of care and treatment, difficulties present when trying to implement such a style of working with arguably more traditional, rural residents as highlighted by Miles (2010).

In terms of methodology, apart from a few exceptions, articles from India were poorly presented and used poor methodologies, which was not the case for the majority of articles which had their basis within the UK. This led to some difficulty with adequately understanding the results which were presented. Secondly whilst filtering the literature to be reviewed, a number of articles were identified which clearly discussed the issue of disability, but failed to mention which type of disability was being referred to until the latter sections of the article or at times not at all. In these instances, a difficulty arose about the relevance of these articles to the review. This led to a dilemma over whether or not to reassess the inclusion criteria in order to include a broader reference base of issues relating to disability generally within the South Asian population. However the decision was taken to exclude articles focussing exclusively on physical disability and to include articles which only partly mentioned intellectual disability. Articles which made no reference to the type of disability being discussed were excluded. This was informed by the key aim of the thesis, namely to review South Asian conceptualisations of intellectual disability. Whether general disability related issues overlap with issues pertaining specifically to intellectual disability was deemed largely irrelevant as the review was not focussed on the interrelationship between the two. The decision made was warranted by the fact that numerous relevant articles were collected, therefore creating a large enough knowledge base focussing specifically on intellectual disability.

Setting up the study

The appeal of carrying out research on the Sikh community was directly related to my own religious orientation which is Sikhism. Not only did my interest in the field of intellectual disability, combined with the lack of literature on the Sikh population generally spur my interest, but I felt well suited to the study aims in terms of having a close insight into Sikh culture, beliefs and key contacts that could help promote the research. Setting up the research involved tailoring the IDLS, the main measure used in this study, to suit the Sikh population and translating it to a Punjabi version.

Modifications made to the IDLS were based on the key tenets of Sikhism based on the only major source; the Guru Granth Sahib Ji as opposed to academic sources, due to their dearth in this field. Translation of the survey into Punjabi was carried out by an overseas company based in India, due to their decrease in cost as well as my own ability to cross-check the translation as well as drawing on the skills of various Punjabi and English literate contacts. Difficulties unfortunately arose whilst attempting to transfer the Punjabi version onto the online system 'OPINIO'. Due to several software difficulties, this process was time consuming and taxing and significantly delayed the promotion date for the overall study. After two months of the study being available online, in both Punjabi and English, the OPINIO software was updated to a newer version, which in turn created errors in the Punjabi versions text. Certain characters were for example replaced by random symbols throughout the entire survey. At this point a decision was required about whether to adjust the errors in the survey. Despite the length of time invested in creating a Punjabi version and uploading it in an accessible format online, it was decided that the time required to adjust the errors was unwarranted because up to this point not a single participant

had completed the Punjabi survey online. Thereafter efforts were made to promote hard copies of the Punjabi survey amongst older, Punjabi speaking adults through snowballing and through Gurdwara recruitment. Efforts involved approaching potential participants directly and informing them of the research and asking younger participants known to the researcher to approach their older relatives directly. Neither proved to be overly fruitful as only two responses were obtained in Punjabi.

Recruitment

As mentioned previously, prior to beginning the promotion of the survey, I felt confident in gaining participants. Initial avenues for recruitment took place via personal contacts who, it was hoped, would promote the research to their contacts through snowballing and incentivised recruitment (Gardner, 2009). The recruitment process however required a huge investment of time and disappointingly resulted in many fewer responses than anticipated. As a result, alternative avenues for recruitment were explored. Numerous attempts were made to contact key members of the UK Sikh community in order to seek their support in promoting the survey. This mainly involved contacting Sikh members of professional bodies, such as Sikh organisations within businesses. In addition, attempts were made to contact speciality Sikh media in the form of three TV channels and various newspapers as well as prominent internet sites in the hope that they would help to promote the research. These efforts were only successful though when personal contacts knew of a key member in these organisations and introduced them to the researcher. As a result, the survey was promoted on the TV channel 'Sikh Channel' and promoted on their blog. Although this seemed advantageous in terms of accessing potential participants, several difficulties arose. No key person was allocated to promote the project, which

resulted in numerous repetitive conversations about the project with several channel employees, who it was felt did not liaise among themselves; agreements in terms of the advertising time were not met; agreed specifications as to the TV advert regarding the research were not enforced and my requests were unfulfilled. In retrospect, attempts to promote the study through Sikh media took up precious time, yet only recruited a small number of participants.

Another avenue of promotion used was Gurdwaras. Requests were made to display posters advertising the survey on notice boards. Two main issues arose from this attempt to promote the research. Firstly, it is unclear whether or not Gurdwaras did actually display the poster as requests were only made by post or e-mail. Secondly, if displayed at all, it is unclear how long the poster was displayed for. Of the Gurdwaras which the researcher accessed in person, posters were either taken down or covered with another notice within a few days of them being displayed.

A final difficulty in promoting the research concerns the mismatch between individuals' enthusiasm to help promote the research versus the actual help offered. A main online Sikh newspaper for example, offered to help with promoting the survey and displayed a high level of interest in the research, yet the promotion failed to take place. This pattern was observed repeatedly throughout the recruitment process.

Despite the difficulties with promoting the survey and accessing key organisations, a few individuals were extremely keen to offer their support and help with no desire for monetary compensation or recognition of any kind. In retrospect, the survey promotion would have benefited from more focussed promotion. Of key importance were my personal contacts. Although in many cases they did not

complete the survey themselves, several individuals guided me in establishing links with other helpful key contact persons. Secondly, Gurdwaras were felt to be an important venue within which to promote the research. However, with hindsight participants could have been gathered from increased focus on a few Gurdwaras as opposed to attempting to target larger numbers of Gurdwaras with limited resources for follow-up. Although I did attempt to promote the research at Gurdwaras by handing out surveys, other approaches may have been beneficial, such as having a stall in order to draw attention; announcing the research within the main venue in order to alert participants; my repeated attendance on particular days of the week in order to target attendees at the Gurdwaras and offer them several opportunities to complete the survey and finally to have more posters displayed at several locations within the Gurdwaras.

Interpreting the data

During the data interpretation stages several issues began to emerge. The first consideration arose regarding the recognition section and applicability of the findings from the nature of the task. Recognition of the symptoms of mild intellectual disability after reading a short vignette led to numerous other categorisations of the difficulties observed. It would have been interesting to see if responses would have differed after a participant was exposed to a short unlabelled video regarding intellectual disability, or perhaps to a labelled vignette, a study carried out by a fellow UCL DCLinPsy trainee concurrently (Connolly, 2011). A vignette methodology, although endorsed by many authors (Angermeyer & Dietrich, 2005; Furnham & Chan, 2004; Jorm, Christensen & Griffiths, 2006), in reality only offers a snapshot into a scenario that participants may actually spend very little time thinking

about prior to answering numerous questions about the difficulties presented. If certain key phrases or words are not taken into account, the validity of responses may well be affected. It is therefore unclear how accurately the results from this task represent a participant's ability to recognise intellectual disability in a real life scenario where interactions are likely to be more complex and embedded with richer information.

Studies of the IDLS have demonstrated good psychometric properties in the context of cross-cultural research (Scior & Furnham, 2011). The translated Punjabi version allowed for the IDLS to be accessible for the Punjabi community and translations into other languages would of course allow for the survey to accessible to other cultural groups. However, certain issues were raised during the process of this research regarding the use of the IDLS and presumably other measures of this standard with non-Western populations.

A small number of participants described difficulties with understanding the survey. Although no formal procedure was used to gather feedback regarding the IDLS, ideas regarding the difficulties encountered by a few participants should be noted. First, key terms within the survey may have been difficult to understand to certain members of the Sikh sample and potentially to other non-Western community members. The terms 'meningitis' or 'genetic factors' for example may hold little meaning to an older female adult with no formal education and whose main role is to care for her family rather than to work. Medical conditions will invariably have different meanings and labels attached to them for members of non-Western cultures.

The whole notion of research and of the importance in taking part needs consideration. A part of mainstream Western culture is the notion of research, either

formal academic research or market research. A common barrier I experienced when attempting to recruit older adults to take part in this study was the view that it was not applicable or relevant to them and that information should be gathered instead from younger members of the community, who may have been regarded as more knowledgeable by older adults. It can only be assumed that for the older adults who refused to take part in the survey, a requirement was perceived to provide correct answers as opposed to honest views, despite attempts of the researcher to clarify that this was not the case. Another reason for a lack of participation may also have been a belief that the research was somehow not relevant to them. A few encounters experienced by the researcher alluded to this, with people saying *'I don't know anyone with learning disability'* for example before walking away and preventing any further explanation regarding the aim of the research. A number of older participants also were unable to read either Punjabi or English and despite offers to offer verbal support with completing the survey, all declined. Another observation made about both the English and Punjabi versions of the survey was made by several participants who felt that neither was written in colloquial language. Admittedly this comment was made by only a handful of participants, and although no details were obtained as to the exact difficulties in the text, this may explain the lack of responses from older adults, some of whom may not have spoken English and not have received a formal education either in the UK or their home country.

Another consideration related to the question whether level of religious adherence can be accurately categorised. Although the approach used in the present study was admittedly not aiming to explore religiosity in great depth, it is important to acknowledge that when studying South Asian cultures, levels of religious practice may play an important role in participants' responses. Religious practices do

however vary enormously, not only between religions, but also between cultural groups. In the West, knowledge regarding religious practices of Eastern religions may only scratch the surface, and so it seems important to approach capturing religiosity through quantitative measurements with caution. Attempts to study the relationship between religion and its effect on responses may have to be weighed up in terms of the overall advantage and disadvantage of this approach. Whilst gathering limited information via the use of a brief rating scale may gather data, the self-reported information gathered fails to provide any real depth of understanding as it is simply a crude measure of the variables in question. The reliability of the self-report may also be worth consideration. When using a rating scale to capture level of religious importance, with a religious group, the issue of reliability has to be considered. Participants belonging to a religious group may feel the need to present themselves as religiously adherent for example, compared to participants who do not adhere to any religion. The self-report method via a rating scale makes it easy to overstate or indeed understate level of engagement with the variable of interest.

Finally, it seemed appropriate to modify the IDLS to the South Asian group targeted by this research. Replacing the word ‘Allah’ for ‘Waheguru’ was necessary as they are two completely separate descriptions of ‘God’ from two separate religious groups. More subtle emphasis on changes such as ‘place of worship’ to ‘Gurdwara’, it is hoped, would have emphasised the relevance of the survey to the Sikh population and increased user-friendliness. Such modification and personalisation is recommended in any attempt to use an existing measure with a particular culture or religious group. Whilst it is acknowledged that different labels and descriptions may have different meanings, it could be argued that the use of the same label with different religious or cultural groups would also have different

meanings. Attempting to use a measure that is designed for a broad range of cultural groups over one particular group will inevitably be advantageous. However in order to ensure optimum levels of user-friendliness, it seems logical to tailor the measure to the cultural group being studied.

Summary

This study was in part an exploration of the beliefs held by the UK Sikh community towards intellectual disability and in part a comparative study examining whether beliefs held towards intellectual disability differed across Sikh and white British groups. A key difficulty concerned promotion of the study among the Sikh public. The findings revealed only small differences between the groups. A similar proportion of each sample was able to recognise intellectual disability; Sikhs were more likely to attribute causes to religion or fate and white British participants were slightly more likely to endorse inclusion. When associated with social distance, the level of religious importance for the Sikh group was similar to the white British sample. The finding of similar levels of stigma between the Sikh and white British samples runs counter to a number of studies that suggest stigma associated with intellectual disability is increased among South Asians (Hatton et al., 2003; Hubert, 2006). However caution is called for in interpreting the present findings as the samples were relatively highly educated and lacked older adult participants. Further attempts to study the Sikh population should incorporate greater focus on a few targeted venues. It may also be useful to explore in more depth levels of religious adherence and its influence on responses. This could be done by sampling religious and non-religious samples from the UK Sikh population.

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Appendices

Appendix 1: Recruitment poster - English version



Important Sikh Survey

You are invited to take part in a study being carried out by
University College London

Very little is known about the needs of the Sikh community

For this purpose we would be grateful if you could take part in our
survey and let others know about it

**For 10-15 minutes of your time you could win up
to £50 in vouchers of your choice**

The survey will provide us with vital information about how the Sikh
community view a range of difficulties in others.

Please contact g.kaur@ucl.ac.uk for further information

Questionnaires available in both Punjabi & English

Punjabi: <https://opinio.ucl.ac.uk/s?S=11034>

English: <https://opinio.ucl.ac.uk/s?S=11049>

Punjabi: <https://opinio.ucl.ac.uk/s?S=11034>

English: <https://opinio.ucl.ac.uk/s?S=11049>

Punjabi: <https://opinio.ucl.ac.uk/s?S=11034>

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Punjabi: <https://opinio.ucl.ac.uk/s?S=11034>

English: <https://opinio.ucl.ac.uk/s?S=11049>

Appendix 2: Recruitment poster - Punjabi version

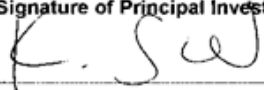


ਸਿੱਖ ਸਮੁਦਾਏ ਦੀਆਂ ਲੋੜਾਂ ਬਾਰੇ ਬਹੁਤ ਥੋੜ੍ਹੀ ਜਾਣਕਾਰੀ ਹੈ

Appendix 3: Ethics letter of approval



Amendment Approval Request Form

| | | |
|--|--|---|
| 1 | ID Number: 0960/001 | Name and Address of Principal Investigator: Dr Katrina Scior Research Dept of Clinical, Educational & Health Psychology UCL |
| 2 | Project Title: Public knowledge and attitudes towards intellectual disability: a cross-cultural and cross-religion study | |
| 3 | Information about the amendment: (a) Is the amendment purely administrative? <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No <input type="checkbox"/> N/A (b) Has the Participant Information Sheet/Consent Form been changed as a result of the amendment? If yes, please enclose a copy. <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> N/A | |
| 4 | Summarise the issues contained in the amendment: 1) I am looking to extend this study to study knowledge about learning disability in more depth, alongside a continued focus on attitudes. For this purpose a new measure has been designed which will be administered alongside the questionnaires used in the original study (copy of all research materials enclosed). 2) The information sheet has been amended- as we are looking to investigate whether respondents can identify on the basis of two vignettes whether a fictitious person has a learning disability or is experiencing mental health problems the study is described in more general terms as concerning "people experiencing difficulties" without explicit reference to learning disability or mental health as this would be leading. 3) Recruitment will be both in person and web based. 4) Given that the early results from this research have been very promising, I have decided to take this work further and have been accepted to complete this study for the purposes of obtaining a part-time PhD (due to register April 2009). Therefore the scale and timeframe of the study will be much larger than originally detailed and completion is not due until March 2013. | |
| 5 | Please give any other information you feel may be necessary: N/A | |
| Signature of Principal Investigator:  | | Date of Submission: 29.1.2009 |

FOR OFFICE USE ONLY:

Amendments to the proposed protocol have been approved by the Research Ethics Committee. until March 2013

Chair's Signature: Phil

Date: 4/2/2009

Please return completed form to:

Secretary of the UCL Research Ethics Committee
Graduate School, North Cloisters, Wilkins Building
Gower Street, London WC1E 6BT